Pre-Death Grief, Resourcefulness and Perceived Stress Among Care Givers of Partners with Young Onset Dementia

Karie Kobiske
Marquette University

PRE-DEATH GRIEF, RESOURCEFULNESS AND PERCEIVED STRESS AMONG CAREGIVERS OF PARTNERS WITH YOUNG ONSET DEMENTIA

by

Karie M. Ruekert Kobiske MSN RN

A Dissertation submitted to the Faculty of the Graduate School,
Marquette University,
in Fulfillment of the Requirements for
the Degree of Doctor of Nursing.

Milwaukee, Wisconsin

August 2018

ABSTRACT
PRE-DEATH GRIEF, RESOURCEFULNESS AND PERCEIVED STRESS AMONG CAREGIVERS OF PARTNERS WITH YOUNG ONSET DEMENTIA

Karie M. Ruekert Kobiske MSN RN

Marquette University, 2018

Over 200,000 Americans are diagnosed with young onset dementia (YOD). YOD is the dementia diagnosed prior to the age of 65. Most persons of YOD are cared for by their partners. Caregiving for a partner diagnosed with YOD has unique challenges including multiple losses resulting from the functional, cognitive, and behavioral declines which can be demanding and stressful. These losses experienced by the caregiver of a partner diagnosed with YOD have been termed pre-death grief. Caregivers of partners with YOD often report high levels of burden and stress resulting in depression, anxiety, hopelessness, as well as increase morbidity and mortality.

Using the theoretical framework of Resilience Theory, this cross-sectional, correlational study examined the moderating effect of a protective factor of resourcefulness, both personal and social resourcefulness, between the relationship of the risk factor of pre-death grief and perceived stress of 104 YOD caregiving partners using an online survey platform.

Results indicated a large positive correlation between pre-death grief and caregiver perceived stress ($r = .65$; $p < .001$). Together pre-death grief, personal resourcefulness and social resourcefulness explained 51.5% of the variance in perceived stress. Personal resourcefulness did not moderate the relationship between pre-death grief and perceived stress. Social resourcefulness did positively moderate this relationship between pre-death grief and perceived stress. These finding creates opportunities to better understand the needs using methodological triangulation before appropriate interventions for caregiving partners of YOD can be established.

ACKNOWLEDGEMENTS

Karie M. Ruekert Kobiske MSN RN

No journey is complete without the support of others. I have been blessed with many people who have supported me and walked with me on this journey – more people than I will ever be able to thank properly.

I was blessed with the best committee. Words cannot express my most sincere gratitude to Dr. Abir Bekhet, my committee chair. Thank you for your endless support, guidance, patience, understanding and so much more. Thank you for always providing valuable direction and all your amazing assistance. Thank you, Dr. Marilyn Frenn, – you are my other champion. Thank you for giving me hope and direction – everything became brighter when you became director of the PhD nursing program. Thank you for being on my committee. Thank you to Dr. Mauricio Garnier-Villarreal for your patience with all my questions, for making stats understandable, and for being on my committee.

I would like to thank all my Marquette family - all the faculty and support staff who have helped me out and cheered me along including Pengpeng Wang, who always had a kind and encouraging word for me. I would have never completed this journey if it was not for Dr. Donna McCarthy – thank you for fighting for me when I had all but given up. Thank you to all of my friends for your support. A special thank you to Dr. Diana Hankes, Dr. Jill Berg, Dr. Lori Cronin, Dr. Heather Vartanian and Dr. Jamie Hansen - each who provided special support on so many occasions. Thank you to the Waukesha County Community Foundation, Peter and Barbara Lettenberger Fund for the funding of my research. Thank you to my in-laws Ron and Ann Kobiske for all your support.

Thank you to my family! My parents Frank and Kay Ruekert instilled a strong sense of education in each of their children. I was caring for my dad when I went for my MSN. He no longer spoke as dementia had taken much of him away from us. One day as I was babbling to him about my MSN and lamenting starting the program, he stopped rocking in the chair, looked up at me and in a weak voice said, “Hang with it Kar.” Those words were my mantra then and now. Thank you, mom, for showing me love, strength and the value of education. Thank you to my step father Peter Lettenberger for all the encouragement, support and love. A special thank you to my sister Linda Ruekert Costello who has been by my side my entire life – Sisters Strong! Thank you to my husband, Bret Kobiske for always believing in me – even when I did not believe in myself. I have been so blessed with the most amazing, supportive and loving children; my sunshines – Aleysha Juntunen, Brittany, Jake and Claire Kobiske – everything I do – I do for you. You are my heart and soul and reason for being. Thank you to my son in law, Cory Juntunen for your support and for providing my other mantra – You got this! You have no idea how many times I have repeated your words to myself over the last 5 years.

Thank you all for walking with me on this journey! My love to all of you!

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Pre-death Grief, Resourcefulness, and Perceived Stress among Caregivers of Partners with Young Onset Dementia

CHAPTER I
Background and Significance

Background

Dementia is a broad term that refers to a decline in cognitive functions that significantly impact a person's ability to perform activities of daily living (Alzheimer's Association, 2018). Alzheimer's disease is the most common form of dementia accounting for up to 80% of all diagnosed dementias (Alzheimer's Association, 2018). Dementia and Alzheimer's disease are frequently used interchangeably by media and the public (Alzheimer's Association, 2018). Young onset dementia (YOD) is the diagnosis of dementia, including Alzheimer's disease, that occurs prior to the age of 65 years old. YOD has been used interchangeably with the terms "early onset dementia" and "early onset Alzheimer's disease" (Alzheimer's Association, 2006). Practitioners prefer the term YOD to avoid confusion between the staging of dementia as "early dementia" or "early Alzheimer's disease" versus diagnosis prior to the age of 65 (Alzheimer's Association, 2018).

Pathophysiological diagnoses of dementias can only be ascertained upon autopsy. Currently, clinicians rely on history and physical data along with laboratory and other imaging tests to confer a probable diagnosis. The diagnosis of YOD has the same criteria as a traditional dementia diagnosis and requires the development of a minimum of two of following symptoms for diagnosis: (1) memory loss, (2) inability or difficulty to focus or pay attention, (3) communication and language difficulties, (4) reasoning and/ or

judgment concerns, and (5) errors in visual perceptions (Alzheimer's Association, 2018). These symptoms result from the deterioration and damage to brain cells that inhibits their ability to communicate with each other (Alzheimer's Association, 2018). Symptoms develop gradually and progress over time. Progression of the symptoms results in a decrease of functioning for the individual which can lead to death. There is currently no known mechanism to halt disease progression and no known cure for YOD (Alzheimer's Association, 2018). YOD has occurred as early as people in their 30's but is more commonly seen in people in their 40's and 50's (Alzheimer's Association, 2018).

Incidence and prevalence of YOD. It is estimated that approximately 5.7 million Americans are living with a diagnosis of dementia (Alzheimer's Association, 2018). Over 200,000 of those people or about 5% of all dementia diagnosis are YOD (Alzheimer's Association, 2018). These statistics are thought to under-represent the actual number of people affected with YOD since there is often a delay in diagnoses due to a perceived stigma and misdiagnosis (Alzheimer's Association, 2018). This under-representation of YOD diagnosis is confirmed in the Health and Retirement Study conducted by the University of Michigan Institute for Social Research and Survey Research Center and the National Institute of Health in 2000, which estimated the incidence for YOD to be as high as 6-10% of all dementias (Alzheimer's Association, 2006). Teles Vieira and colleagues (2013) found wide ranges for the incidence and prevalence of YOD during a review of literature. In published studies, the prevalence of YOD ranges from "0 to 700 per 100,000" people (Teles Vieira et al., 2013, p. 93) while the incidence of YOD ranges "between 8.3 to 22.8 new cases per 100,000" (Teles Vieira et al., 2013, p. 93) for people under 65 years old. These wide ranges were thought to be

related to the specific population being studied, the etiology of the dementia being studied, and the geographic area of the conducted study (Teles Vieira et al., 2013). One note of interest is that many of these YOD studies were conducted outside of the United States (Teles Vieira et al., 2013). One constant found in the literature review by Teles Vieira et al. (2013) was that the incidence of YOD increases as age increases.

Diagnostic difficulties and potential costs related to YOD. The under-diagnosis of YOD is supported in reports from the caregiver partners as they often describe difficulties in obtaining the diagnosis (Alzheimer's Association, 2006). Frequently, initial diagnosis is incorrect as health care practitioners are not expecting dementia in people under the age of 65 years (Svanberg, Spector, & Stott, 2011). These persons are often misdiagnosed initially with depression, stress, marital problems, menopause or other mental health concerns with implications of the person having a "mid-life crisis" (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2014; Flynn & Mulcahy, 2013; Roach, Keady, Bee, & Hope, 2009; Svanberg et al., 2011).

The diagnosis of YOD has financial implications for the person diagnosed with YOD, the caregiving partner, the family, and society. In 2016, 15 million American family and friends provided unpaid care to persons diagnosed with Alzheimer's disease and other dementias totaling 18.4 billion hours which is valued at $232 billion and is nine times the total revenue of McDonalds in 2016 (Alzheimer's Association, 2018). The financial impact of the diagnosis of YOD on a family often severely destabilizes the family's financial security due to income loss and increased health care costs (Werner, Stein-Shvachman & Korczyn, 2009).

Significance of the study

Caregiving for a partner diagnosed with YOD has unique challenges including multiple losses (Alzheimer's Association, 2006; Flynn & Mulcahy, 2013; Romero, Ott, & Kelber, 2014; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). These losses include job loss, financial loss, companionship loss, social loss, personal loss which includes loss freedom, recreation opportunities, identity and health that occur as a result of the caregiving experience, and ambiguous loss that occurs when the life partner is physically present but not able to be part of the dynamic psychosocial relationship (Frank, 2007; Noyes et al., 2010; Svanberg et al., 2011; Wachol-Biedermann et al., 2014). This loss is operationalized as caregiver grief. Caregiver grief is defined as psychosocial responses to valued loss (Meuser, Marwit, & Sanders, 2004). This grief is modified to include pre-death grief which describes the phenomena family members experience as they watch the social and intellectual death of their loved one due to dementia (Mauser et al., 2004). Pre-death grief is a shared experience of caregivers of partners diagnosed with YOD (Svanberg et al., 2011; Wachol-Biedermann et al., 2014). The negative impacts of pre-death grief on the physical, psychological, social, and financial status of caregivers of partners with YOD are well documented in the literature (Chan, 2010; Holley & Mast, 2009; Lindauer & Harvath, 2014; Noyes et al., 2010; Paun et al., 2015; Romero et al., 2013; Shuter, Beattie, & Edwards, 2013).

Though not exclusive to caregivers of YOD, the impact of these losses is different in YOD due to the life timing of the disease that affect the employment status and the family dynamics as there are often dependent children still residing in the home (Alzheimer's Association, 2006; Ducharme, Kergoat, Antoine, Pasquier, & Coulomb,

2013; Flynn, & Mulcahy, 2013; Kaiser & Panegyres, 2007). Financial losses can result from a decrease of at least one family income source (Alzheimer's Association, 2006). Additional financial implications are realized as the person diagnosed with YOD is often kept in their home longer due to the disease trajectory of the YOD, the age of onset, and the family dynamics (Svanberg et al., 2011). Caregivers often receive no financial reimbursement (Alzheimer's Association, 2018). The financial implications of YOD contribute to perceived stress of the caregiver and are detrimental to their general well-being (Ducharme et al., 2014; Flynn & Mulcahy, 2013; Rosness, Haugen, Gausdalh, Sjora & Engedal, 2012).

In addition to the experience of multiple losses with YOD, caregiving challenges include changes in family dynamics. Caregivers of partners with YOD attempt to "juggle" all previous roles while now assuming all parenting of children and all household tasks which result in increased perceived stress and threaten caregiver well-being (Ducharme, et al., 2013; Ducharme et al., 2014; van Vliet et al., 2010).

Wawrziczny, Pasquier, Ducharme, Kergoat, and Antoine (2017) found that needs of caregivers of YOD differ from traditional dementia caregivers in four main areas related to the age of YOD caregivers. YOD caregivers have a greater need to maintain contact and communication with others as they face the loss of socialization with their partners (Wawrziczny et al., 2017). Resources are often limited and difficult to locate for people diagnosed with YOD. Caregivers for people with YOD express the need to have professional assistance in the navigation for resources that may be vital to the maintenance of the home as the family experiences financial losses (Wawrziczny et al.,

2017). Additional needs included age appropriate care for those with YOD and decreasing the stigma that often accompanies this diagnosis (Wawrziczny et al., 2017).

These challenges and the resulting stress relating to caregiving are well documented (Aria, Matsumoto, & Aria, 2007; van Vliet et al., 2010; Ducharme et al., 2013). An estimated 59% of all dementia family caregivers rated their stress as high or very high, 56% rating high financial strain, and 44% of all dementia caregivers experiencing depressive symptoms (Alzheimer's Association, 2018; Fischer, et al., 2011). The physical strain of caregiving can exacerbate existing conditions specifically high blood pressure and diabetes (Alzheimer's Association, 2018; Christakis & Allison, 2006; MetLife Mature Market Institute, 2006; National Alliance for Caregiving and AARP, 2009; von Kanel, et al., 2006). Caregivers to partners diagnosed with YOD reported higher levels of caregiver depression (Aria et al., 2007; Kaiser & Panegyres, 2007; van Vliet, et al., 2010).

Yet some caregivers of partners diagnosed with YOD can adapt to these challenges of loss and perceived stress with some even reporting an enhanced meaning in life through this caregiving experience (Deist & Greeff, 2015; Smith-Osbourne & Felderhoff, 2014). These caregivers are said to be resilient.

Theory

Resilience theory provides the theoretical framework for this study (Richardson, 2002; Rutter, 1985). Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress." (American Psychology Association, 2014, p. 4). Resilience theory proposes resilience as

a dynamic process of balancing risk and protective factors in the face of adversity and offers insight into why some caregivers adapt to adversity while others struggle. Adversity involves a "negative life circumstance" (Luther & Cicchetti, 2000, p. 858) which for this population are the losses and challenges imposed by the diagnosis of YOD. Resilience in caregivers of partners diagnosed with YOD is important for enhancing overall wellbeing for both the caregiver and the partner diagnosed with YOD (Ducharme et al., 2013; Earvolino-Ramirez, 2007; Flynn & Mulcahy, 2013; Herrman, et al. 2011; Rosness et al., 2012; Wald, Taylor, & Asmundson, 2006).

Protective factors can enhance resilience by balancing out risk factors (Fletcher & Sarkar, 2013; Rutter, 1985). Resourcefulness is the ability to problem solve when faced with adversity and has two components (Zauszniewski, Lai, & Tithiphontumrong, 2006). Personal resourcefulness is the ability to self-help or rely on one's own abilities, and social resourcefulness is the ability to seek help from others (Zauszniewski et al., 2006). Resourcefulness is a potential protective factor that may moderate the relationship between pre-death grief and perceived stress of the caregiver by reducing the effects of the risk factor of pre-death grief, thereby contributing to the reduction of perceived stress of the caregiver's increasing caregiver well-being. (Bekhet, 2013; Zauszniewski, Bekhet, & Sureskey, 2010; Zauszniewski et al., 2006). To date, no known research has examined the moderating effects of resourcefulness on the relationship of pre-death grief and perceived stress among caregivers of partners with YOD.

Purpose of the study

A model of care for people diagnosed with YOD must include the care partner (Flynn & Mulcahy, 2013; Smith-Osbourne & Felderhoff, 2014). Therefore, the purpose

of this study is to examine for a relationship between caregiver pre-death grief and the caregiver perceived stress. Using the theoretical framework of resilience theory, this quantitative study investigated the potential moderating effect of the protective factor of resourcefulness on the relationship between pre-death grief and caregiver's perceived stress, looking specifically at the two constructs of personal and social resourcefulness (Zauszniewski et al., 2006). Each of these constructs can be tested for moderation on the relationship of pre-death grief and perceived stress in a caregiver of a partner with YOD. An understanding of the potential relationship of these variables enables the design and integration of future interventions to benefit caregivers and subsequently benefit the partner diagnosed with YOD, the care recipient (Cherry, Salmon, Dickson, Powell, & Sikdar, 2013).

Specific aims and hypotheses. The specific aims, research questions, and hypotheses of this study are:

Aim 1: To examine the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis1: Caregiver pre-death grief has a positive association with caregiver perceived stress in caregivers of a partner with YOD.

Aim 2: To determine whether personal and/or social resourcefulness moderate the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2a: Personal resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2b: Social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Key variables

This concept of resilience has been an established and explains why some individuals maintain or thrive in response to adversity and others do not (Cabanyes Truffino, 2010). Resilience theory provides the theoretical framework for this study as it examines the interaction of protective factors and risk factors (Bekhet, 2013; Zauszniewski, Bekhet, & Suresky, 2009). Resilience is defined as the ability to overcome adversity (Bekhet, 2013; Zauszniewski et al., 2009). The adversity in this study was caregiving for a partner diagnosed with YOD.

Pre-death grief. Pre-death grief is the independent variable in this study. It is defined as grieving before the physical occurrence of the loss (Lindauer & Harvath, 2014; Meuser & Marwit, 2001; Noyes et al., 2009). Pre-death grief differs from anticipatory grief because there is a disruption in the relationship and in the communication with the person who is the care recipient (Lindauer & Harvath, 2014). This phenomenon of pre-death grief is a shared experienced among caregivers of persons with dementia (Lindauer & Harvath, 2014; Marwit & Meuser, 2005). This loss of the personhood of the care recipient is the major component of pre-death grief for caregivers of partners with YOD (Lindauer & Harvath, 2014; Marwit & Meuser, 2005). The concept of pre-death grief in caregivers of persons with YOD is characterized by the continual loss that occurs as a result of the disease progression and trajectory (Blandin & Pepin, 2015; Lindauer & Harvath, 2014). This study assessed for the possible relationship between a caregiver's

level of pre-death grief and their level of perceived stress. Additionally, this study examined if the protective factors of resourcefulness, both personal and social, moderate this relationship.

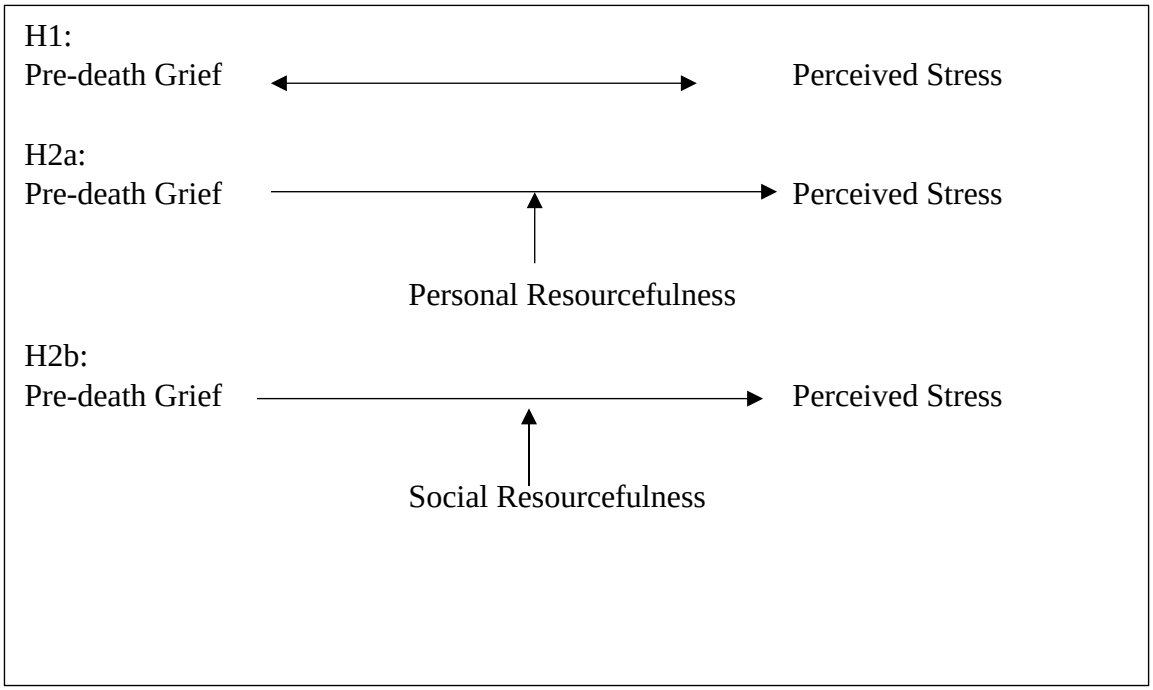
Perceived stress. Perceived stress was the outcome variable for this study. Perceived stress is a result of how unpredictable, uncontrolled, and overloaded and individual finds life events (Cohen, Kamarck & Mermelstein, 1983). In 2004, the Alzheimer's Association along with the National Alliance on Caregiving concluded that caregivers for persons with dementia carry a uniquely heavy caregiving burden due to the physically and emotionally demanding caregiving role of persons with dementia. This burden takes a heavy toll on family life resulting in high levels of stress (Wilks & Croom, 2008). Allen and colleagues (2017) concluded, in a systematic review examining the psychobiological burden of caregiving for persons with dementia, the chronic stress of dementia caregiving results in sustained elevated cortisol level and altered immune functioning which has been associated with depression and the development or exacerbation of chronic illness. Perceived stress decreases psychological well-being which Kiefer (2008) defined as "the state in which the individual can fulfill an active role in society, interacting appropriately with others, and overcoming difficulties without major distress or disturbances in behavior" (p. 246). Literature supports that poor psychological well-being has significant impact on quality life, morbidity, and mortality (Donaldson & Donaldson, 1998; Kiefer, 2008). Perceived stress has been associated with increased morbidity and mortality and decreased psychological well-being. In this study, perceived stress by the caregiver was examined as an outcome variable in relation to pre-death grief and how this relationship maybe impacted by resourcefulness.

Resourcefulness. Resourcefulness has been found as a protective factor for caregivers (Bekhet. 2013; Zauszniewski et al., 2006; Zauszniewski, McDonald, Krafick & Chung, 2002). Resourcefulness was originally defined as behaviors and skills that allow for adjustment against disruption (Rosenbaum, 1990). More recent definitions of resourcefulness include two complimentary parts known as personal resourcefulness and social resourcefulness (Zauszniewski et al., 2006). Personal resourcefulness is the ability to function and maintain daily independence (Bekhet. 2013; Zauszniewski et al., 2006). Whereas, social resourcefulness is the ability to seek out, find, and ask for help when needed (Bekhet. 2013; Zauszniewski et al., 2006). Zauszniewski and colleagues (2006) stated that personal and social resourcefulness "should be viewed as two complementary dimensions" of resourcefulness that both are important for well-being (p. 58). This study assessed personal and social resourcefulness individually as protective factors that potentially act as a moderating variable on the relationship between pre-death grief and perceived stress of the caregiver of partners with YOD.

Figure 1.1 depicts the relationship among these variables of the study hypotheses.

Figure 1.1

The study hypotheses



Rationale for study

Previous research has shown positive outcomes on psychological well-being for traditional dementia caregivers who are resilient (Aria et al, 2007; Cabanyes Truffino, 2010; Ducharme et al., 2014; Gibson, Anderson, & Acocks, 2014). To date, no research has investigated the possible moderating effect of resourcefulness on the relationship between pre-death grief and perceived stress among YOD caregivers as proposed in this study. Caregiver well-being is negatively impacted by pre-death grief as the ever-increasing caregiving demands place these caregivers at risk for long term mental and physical health consequences including possible premature death (Paun et al., 2015). These caregivers of partners diagnosed with YOD experience multiple losses including

personal, social, financial, companionship, and intimacy (Rosenthal Gelman & Greer, 2011; Svanberg et al., 2011). Pre-death grief experienced by caregivers of partners diagnosed with YOD has been shown to be different from depression and be associated with higher mental health morbidity and decreased psychological well-being (Meuser et al., 2004; Wachol-Biedermann et al., 2014). Understanding the pre-death grief experience of caregivers of partners diagnosed with YOD in relation to perceived stress and the effects resourcefulness, both personal and social, on this relationship enables the development of interventions and services with a goal of decreasing caregiver morbidity and mortality and increasing caregiver well-being. The ultimate goal of this study is to develop further studies that serve to decrease the caregivers' stress and to enhance their well-being, which have an impact on the caregiver as well as their care-recipient (persons with YOD).

Significance to nursing and contribution to knowledge. Once the relationship of pre-death grief and perceived stress of the YOD caregiver along with potential moderating variables of caregiver personal and social resourcefulness are determined, meaningful programming, interventions, resources, and support systems can be developed. Meaningful programming, interventions, resources and support systems enhance caregiver well-being and allow for the partner to remain cared for in their own home which also keeps the family intact longer (Cherry et al., 2013; Ducharme et al., 2013; Paun et al., 2015; Svanberg et al., 2011; Wachol-Biedermann et al., 2014). Nurses are in a unique position to educate caregivers on disease trajectory and available resources. The results of this study provide insight into whether resourcefulness may help caregivers of partners with YOD cope with their adversity.

This study is aligned with the goals of the *Wisconsin Dementia Care System Redesign: A plan for a dementia-capable Wisconsin* which was published in February 2014 by the Wisconsin Department of Health Services- Division of long term care. Even though many of the goals of their agenda speak most directly to the traditional person diagnosed with dementia who is over 65 years old, there are applications that can transfer to YOD. In agenda item 5.1.3, the aim is to provide support for family caregivers. Under this item, it is recognized that "programs to support family caregivers can significantly delay the need for institutional care and reduce the costs to Medicaid program" (Wisconsin Department of Health Services, 2014, p. 16). Key strategies under this goal are to expand access to caregiver education and support programs. It is under this strategy that the research from this study benefits caregivers for partners diagnosed with YOD.

Potential for leading to future research. Caregivers of YOD report high levels of caregiver stress (Aria et al., 2007; Ducharme et al., 2013; Kaiser & Panegyress, 2007). Since the detrimental effects of caregiver stress has been well documented, an assessment of variables that can be protective and enhance resilience in the face of risk leads to intervention studies that have the potential to decrease perceived stress and enhance caregiver well-being. One risk factor that may contribute to caregiver stress is pre-death grief. If pre-death grief accounts for variance in the perceived stress of the caregiver, addressing this relationship may lead to increased caregiver well-being and adaptation. This can guide the development of appropriate and meaningful programs, interventions, resources and support systems to assist caregivers as they care for a partner diagnosed with YOD (Aria, et al., 2007; Armani, Jarmolowicz, & Panegyress, 2012; Cherry et al., 2013; Ducharme, et al., 2013; Kaiser & Panegyres, 2007; Svanberg, Stott, & Spector,

2010; van Vliet et al., 2010). Caregivers of partners with YOD are searching for meaningful support and resources to address their needs (Ducharme et al., 2013; Ducharme et al., 2014; Flynn & Mulcahy, 2013; Gibson et al., 2014; Rosness et al, 2012). Development of proper programming, interventions, resources and support systems, is predicted to decrease caregiver stress along with an overall increase in caregiver wellbeing. (Armani et al., 2012; Deist & Greeff, 2015; Smith-Osbourne & Felderhoff, 2014; Sun, 2014).

Summary

The diagnosis of YOD is devastating for not only the persons who are diagnosed with YOD but also their families (Ducharme et al., 2014). The losses and challenges that accompany this diagnosis are a risk factor for the caregiving partner that can negatively impact their well-being (Deist & Greeff, 2015). This potentially negative impact does not only jeopardize the caregiving partner's well-being, but also increases their risk for morbidities and /or premature mortality (Sun, 2014). This can result in not only the inability of the caregiver to take care of their partner but also themselves, which would have further financial impact on health care costs (Alzheimer's Association, 2018; Ducharme et al., 2014; Sun, 2014). Using Resilience theory as a framework, this study explores a relationship not only between the risk factor of pre-death grief as related to caregiver's perceived stress, but also on the variable of resourcefulness, both personal and social, as a possible moderator on this relationship. The aim of this study is to determine the moderating effects of personal and social resourcefulness on the relationship of pre-death grief and perceived stress with the goal of developing interventions to enhance caregivers' well-being.

Dissertation chapters' overview

Chapter one has focused on an introduction to the problem and population to be studied. Chapter one reviewed background data and introduced the purpose of this study along with the hypotheses and aims of the study. Chapter two offers a detailed description of the theoretical framework along with the conceptual underpinnings for this study. Chapter three contains a detailed description of the research design and methodology that were used to accomplish this study. The manuscript option was chosen for this dissertation. Two manuscripts take the place of chapters four and five. The first manuscript presents a concept analysis for resilience in caregivers of partners diagnosed with YOD. The second unique manuscript presents the results from this study related to the specific aims, hypotheses and research questions. This manuscript is located in Appendix C.

CHAPTER II
Review of the Literature

In this chapter, the theoretical underpinnings for the study are explored. This study has a positivism paradigm and is to be the first in a line of research, which is assessing the moderating effect of resourcefulness, both personal and social, on the relationship of pre-death grief and perceived stress among caregivers of partners with YOD. The goal is to build authentic knowledge through measurable evidence on these relationships so to later develop and test interventions to benefit these caregivers. This chapter includes a description of resilience theory, which is the guiding theoretical framework for this study. Then, the conceptual, theoretical, and empirical structures (CTES) of this study are discussed. The CTES addresses both vertical and horizontal relationships that demonstrate progression from conceptual definitions to how these concepts are operationalized and measured (Fawcett, 1999). Current knowledge on pre-death grief, resourcefulness, and perceived stress as related to caregivers of YOD is in the review of the literature with gaps of knowledge identified.

Philosophy

The philosophical underpinnings of this study are grounded in positivism. This study examines the phenomenon of pre-death grief with caregivers of partners with YOD as it relates to perceived stress and the possible moderating effect of resourcefulness. The positivism paradigm explains potential relationships by allowing for objective gathering of data on the phenomena of pre-death grief and perceived stress of caregivers of partners diagnosed with YOD in pursuit of true nature of this reality (Guba, 1990). In alignment with the positivism paradigm, the concepts of pre-death grief

and perceived stress were operationalized so that measurement is possible using reliable and valid instruments (Guba, 1990).

The research paradigm consists of the overlap of the ontological, epistemological, and methodological aspects of the philosophy. Ontology is the study of how a philosophy describes the nature of reality. A positivist philosophy views reality as external and objective (Gray, 2013). Positivists find truth in measurable "regularities" of variables and strive for the knowledge of reality and how "it" truly works (Gray, 2013; Guba, 1990; Persson, 2010). Understanding the phenomena of pre-death grief in a quantifiable manner as it relates to perceived stress allows for generalization that are context-free and value free (Guba, 1990).

Epistemology is the study of the nature of knowledge and how knowledge can be justified over opinion. In a positivist paradigm, the epistemology is objective and unbiased (Guba, 1990; Persson, 2010). The researcher focuses on the fact while formulating and testing hypotheses and without interaction within the study (Gray, 2013). Pre-death grief, perceived stress, and resourcefulness were studied using objective instruments in a survey format.

Methodology is the manner of data collection during the research process. Positivism lends to quantitative research. Quantitative research focuses on measurement, validation and generalization. "It involves statistics, surveys and questionnaires, and the measurement of phenomena which are mathematically analyzed" (Geanelios, 1992, p. 16). Knowledge gained from objective measurement of the potential relationship of pre-death grief and perceived stress and the effect of resourcefulness on this relationship from

this study allow knowledge on this relationship on how it really exists and for the development of meaningful interventions in the future.

Using a positivist approach, resilience theory offers an exemplar for measuring the protective factor of resourcefulness on the potential relationship of pre-death grief and perceived stress among caregivers of partners with YOD. The empirical referents used in this study assessed and measured the participant's grief and stress along with their resourcefulness skills, both personal and social.

Vulnerable population

Caregiving for people with dementia including YOD most often is undertaken by family members (Alzheimer's Association, 2006). The progressive nature of dementia combined with the challenges of functional, cognitive, and behavioral declines can make caring for persons with dementia uniquely demanding and stressful (Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016). Dementia caregivers including YOD caregivers report high levels of burden and stress resulting in increased incidence of depression, anxiety, and hopelessness (Alzheimer's Association, 2006; Kaiser & Panegyres, 2006; Petriwskyj et al., 2016). Rosness, Mjorud, and Engedal (2011) concluded primary caregivers of life partners with YOD had an increase in symptoms of depression. Additionally, caregivers of persons with YOD report increased exacerbations of chronic physical illnesses such as cardiac disease and diabetes (Alzheimer's Association, 2006; Petriwskyj et al., 2016; von Kanel et al., 2006). High levels of stress associated with caregiving for partners with YOD increase the risk of morbidity and mortality and produce a vulnerable population (Alzheimer's Association, 2006; Aria et al., 2007;

Ducharme et al., 2013; Kaiser & Panegyress, 2007; Petriwskyj et al., 2016; von Kanel et al., 2006).

Theoretical/ conceptual framework

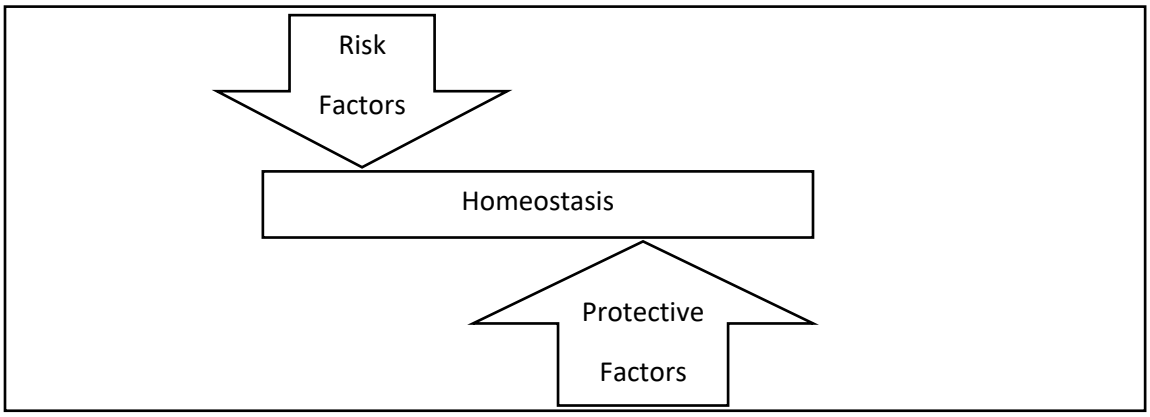
The stress of caregiving for partners with YOD and resultant psychosocial problems are well documented in the literature. This stress and psychosocial distress often result in depression (Kaiser & Panegyres, 2006; Petriwskyj et al., 2016), physical illness (Petriwskyj et al., 2016; von Kanel et al., 2006) or both. However, not all YOD caregivers succumb to increased risk for mental and physical morbidities. These YOD caregivers are said to be resilient. Resilience theory helps explain why some caregivers of partners with YOD struggle with the caregiving experience and others do not. Resilience theory considers the interplay between risk factors and protective factors that individual employs during adversity (Rutter, 1985). Resilience is not a static trait but a dynamic process (Rutter, 2012: Southwick et al., 2014). An individual may successfully cope in one situation and struggle in another which may depend on the individual's vulnerability, development, and interaction with their environment at that time (Rutter, 1985: Southwick et al., 2014). This vulnerability is dependent on the individual's balancing of risk and protective factors (Rutter, 1985).

Resilience theory. Resilience theory is a problem-orientated theory with a goal of promoting positive adaptation. It can be used as a theoretical framework to guide research on relationships among risk factors and to develop interventions that enhance protective factors (Richardson, 2002). Resilience theory explains how homeostasis can be restored after a disruption. An adverse event disrupts the homeostasis and adaptation occurs as risks are balanced with protective factors and a new normal is achieved

(Richardson, 2002; Rutter, 1985). Balancing of risk and protective factors determines the resulting adaptation which can have a positive or a negative outcome (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski & O'Flaherty, 2013; Richardson, 2002; Rutter, 1985; Windle, 2011). The positive outcome is a new normal that results when the homeostasis is restored after adversity. This is termed resilience reintegration which includes new insight and growth from a disruptive experience (Richardson, 2002). Figure 2.1 illustrates the balance of risk and protective factors. The constructs of resilience theory include risk factors, protective factors and adaptation.

Figure 2.1

Resilience theory balance of risk & protective factors



***Risk factors and adversity*.** Risk factors are physical or psychosocial elements that place an individual in jeopardy of maladaptation (Rutter, 1985). Physical risk factors can be biological or environmental in nature. Whereas, psychosocial risk factors involve emotions and affect relationships. Risk factors can magnify an individual's vulnerability (Rutter, 1985). Increased vulnerability may lead to decreased resilience and increased likelihood of a maladaptive outcome (Rutter, 1985).

Adversity has been defined as an event or occurrence that is interpreted as being traumatic or stressful either physically and/or psychosocially by an individual (Garcia-Dia et al., 2013). In other words, adversity is a negative event or a stressor that is perceived by the individual which in turn can influence his/her adaptation (Rutter, 1985). For YOD caregiving partners, the adversity can be the losses and challenges imposed by the diagnosis of YOD, which can cause disruptions in caregivers' homeostasis. In brief, caregivers of partners diagnosed with YOD experience disruptions that occur as a result of the YOD diagnosis, which can result in pre-death grief (Richardson, 2002).

Protective factors. Protective factors are elements that modify an individual's risk in an adverse situation by eliminating or reducing the effects of these risk factors (Rutter, 1985). The protective factors may not operate the same in everyone. Protective factors are individualized and contextual and vary in each person in each situation. Thereby, it is difficult to generalize that protective factors are causal or predictive in their nature as they are individualized to person and situation (Rutter, 1985). Even though these protective factors may operate differently and benefit individuals to different degrees, the literature indicates that there are common protective factors for caregivers of persons with dementia. Some of these protective factors include spirituality (Deist & Greeff, 2015), positive outlook (Deist & Greeff, 2015; Petriwskyj et al., 2016), and resourcefulness (Petriwskyj et al., 2016; Zauszniewski et al., 2016).

Adaptation. According to Richardson (2002), adaptation/reintegration can take four different forms depending on the balance between risk and protective factors. Reintegration is the adaptation to the new normal that follows the homeostatic disruption as a result of adversity. The optimal goal is resilient reintegration, in which growth and

insight are experienced through adversity. Resilient reintegration optimizes well-being resulting in psychological growth. However, positive adaption can occur, yet psychological growth might not happen. Richardson (2002) calls this type of reintegration as back to homeostasis in which the individual may heal but not use the opportunity to grow or strengthen. The individual just gets through the adversity. A third type of adaption is recovery with loss in which an individual not only does not grow but also loses hope and motivation. The final type of adaption is dysfunctional reintegration in which an individual employs destructive behavior to cope with the adversity.

Concept of resilience. Resilience is an established concept that is used in various disciplines all which incorporate the common element of rebounding or the ability to bounce back (Herrman et al., 2011; Earvolino-Ramirez, 2007; Wald et al., 2006). The concept of resilience was first studied in the field of psychology with children who seemed to succeed as adults despite adverse childhood conditions (Herrman et al., 2011; Earvolino-Ramirez, 2007; Wald et al., 2006). In physics, engineering, and physical sciences, resilience is conceptualized as material strength and the ability of the material to return to its original shape (Cabanyes Truffino, 2010; Earvolino-Ramirez, 2007; Gillespie, Chaboyer, & Wallis, 2007). In ecology, resilience describes nature's ability to rebound and regenerate after environmental insult (Cabanyes Truffino, 2010; Earvolino-Ramirez, 2007). In microbiology, resilience is conceptualized as the ability to regenerate on a cellular level (Cabanyes Truffino, 2010; Earvolino-Ramirez, 2007). Resilience is also applied in business with corporate trends, money, production, and the stock market with their ability to bounce back from economic or market downturns (Earvolino-

Ramirez, 2007). Educators use the term resilience when describing student achievement in overcoming barriers (Cabanyes Truffino, 2010). In the social sciences, such as psychology, social work, and nursing, resilience research has shifted from examining negative or risk factors to examining positive or individual strengths that contribute to healthy development and positive coping (Fletcher & Sarkar, 2013; Windle, 2011; Richardson, 2002). A round table of interdisciplinary experts in resilience concluded that the definition of resilience is determined by the context of the study (Southwick et al., 2014). The common denominator in all areas is the ability to overcome adversity (Herrman et al., 2011; Earvolino-Ramirez, 2007; Wald et al., 2006). The ability to be resilient could be important for decreasing caregiver stress and enhancing overall wellbeing for both the caregiver and the partner diagnosed with YOD (Herrman et al., 2011; Earvolino-Ramirez, 2007; Wald et al., 2006).

Previous research in the social and behavioral sciences has treated resilience as a personality trait, a process, and an outcome (Cabanyes Truffino, 2010; Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Gillespie et al., 2007; Herrman et al., 2011; Southwick et al., 2014; Windle, 2011). Currently, resilience is viewed not as a static state but as a dynamic one, with current definitions supporting resilience as a process that is best described on a continuum that changes in response to an individual's perception of the stressor (Herrman et al., 2011; Southwick et al., 2014). Resilience has various definitions including "a process of effectively negotiating, adapting to, or managing significant sources of stress or trauma" (Windle, 2011). The process of resilience is a characterization of adaptation involving growth, strength, and recovery through distress and difficulty (American Psychological Association, 2014). The process of resilience

recognizes distress and hardship and that life can be painful, but individuals work through difficulties to recover resulting in growth (American Psychological Association, 2014).

Resilience and YOD caregivers. Caregivers of partners with YOD must balance risk factors and protective factors as they attempt to adapt to their new normal following a diagnosis of YOD. Caregivers of partners with YOD have experienced challenges prior to receiving the diagnosis of YOD. Caregiving partners have expressed frustration over the delay in obtaining a diagnosis and then relief once the diagnosis was identified as they now have an explanation for their partners' symptoms and behaviors (Alzheimer's Association, 2006; Locheridge & Simpson, 2012; Roach et al, 2009; Svanberg et al., 2011). Some of the challenging behaviors displayed by the partner diagnosed with YOD include: wandering, losing items, forgetting, repetition, agitation, anger, and sleep disturbances (Alzheimer's Association, 2018). Partners report that managing these behaviors is one of the most difficult areas of caregiving for their partners diagnosed with YOD (Ducharme et al., 2013; Locheridge & Simpson, 2012; Roach et al, 2009; Svanberg et al., 2011). Challenges remain throughout the disease trajectory for the caregivers (Flynn & Mulcahy, 2013); when one challenge is conquered, new challenges appear for the YOD caregiver (Aria et al., 2007; Ducharme et al., 2013; Flynn & Mulcahy, 2013).

Even though caregivers express initial relief with the diagnosis, they later describe feelings of being unprepared to cope with a partner diagnosed with YOD and care for their partner as the disease progresses (Ducharme et al., 2013; Locheridge & Simpson, 2012; Svanberg et al., 2011). The progressive nature of the dementia disease causes increase in caregiving needs by the person diagnosed with YOD. Caregiving partners report feeling conflicted as their partners are given a terminal diagnosis, yet they are

discharged from the hospital and expected to go home and to manage (Flynn & Mulcahy, 2013; Roach et al., 2009). As the disease progresses, the person diagnosed with YOD becomes more dependent on the caregiver. This dependency results in adjustment of role and function of the caregiver, potentially threatening caregiver well-being (Svanberg et al., 2011). These challenges faced by caregivers of a partner with YOD often result in high levels of caregiver perceived stress (Ducharme et al., 2013; Petriwskyj et al., 2016).

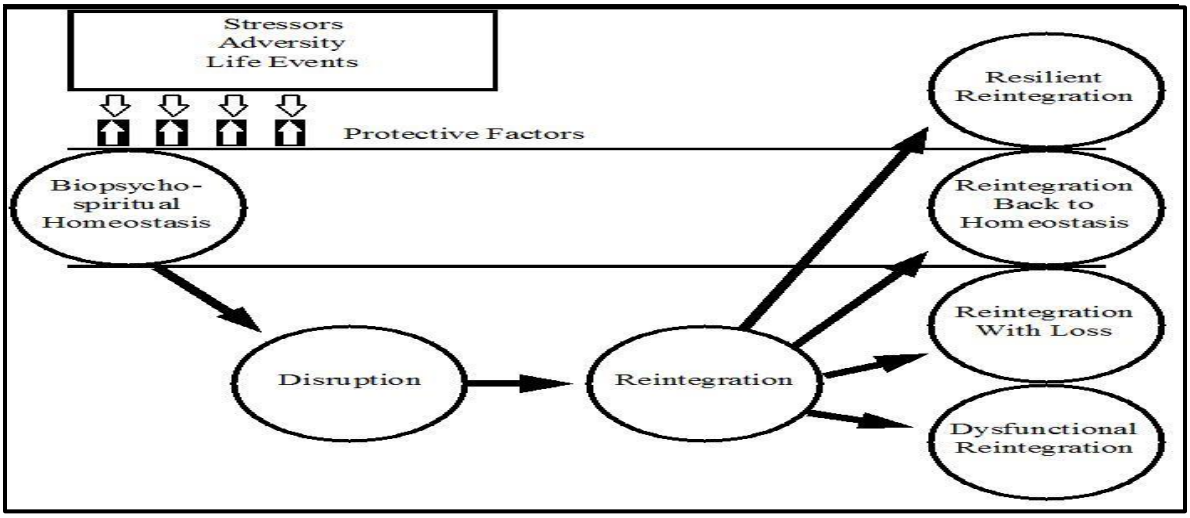
Resilience theory and YOD caregivers. Resilience theory offers the guiding framework for this study as it provides a practical approach to evaluate caregivers' risks and protective factors. Resilience theory is based, in part, on studies that found similar characteristics in individuals who survived trauma with no negative emotional or physical consequences (Richardson, 2002). These characteristics became known as risk or protective factors. Resilience theory is based on the interplay between risk and protective factors in face of adversity. The concept of resilience is defined as a dynamic process explaining how adaptation occurs after an adversity (Rutter, 1985). Resilience is known as the ability to "bounce back" in common vernacular, which reflects positive adaptation and occurs when the protective factors outweigh the risk factors.

Richardson (2002) proposed a model that depicted the interactions of risk and protective factors and the resulting levels of adaptation after an adverse event. Richardson classified risk factors as disruptions in his model. Figure 2.2 represents Richardson's model of Resilience Theory. Protective factors are attributes that reduce or mitigate risk or adversity (Richardson, 2002; Rutter, 1985). Studies have determined that some of the protective factors that are attributes for resilience for caregivers of partners with dementias including YOD are spirituality, positive attitude, resourcefulness, and a

supportive social network (Cherry et al., 2013; Deist & Greeff, 2015; Petriwskyj et al., 2016).

Figure 2.2

Richardson's model of resilience theory (2002)

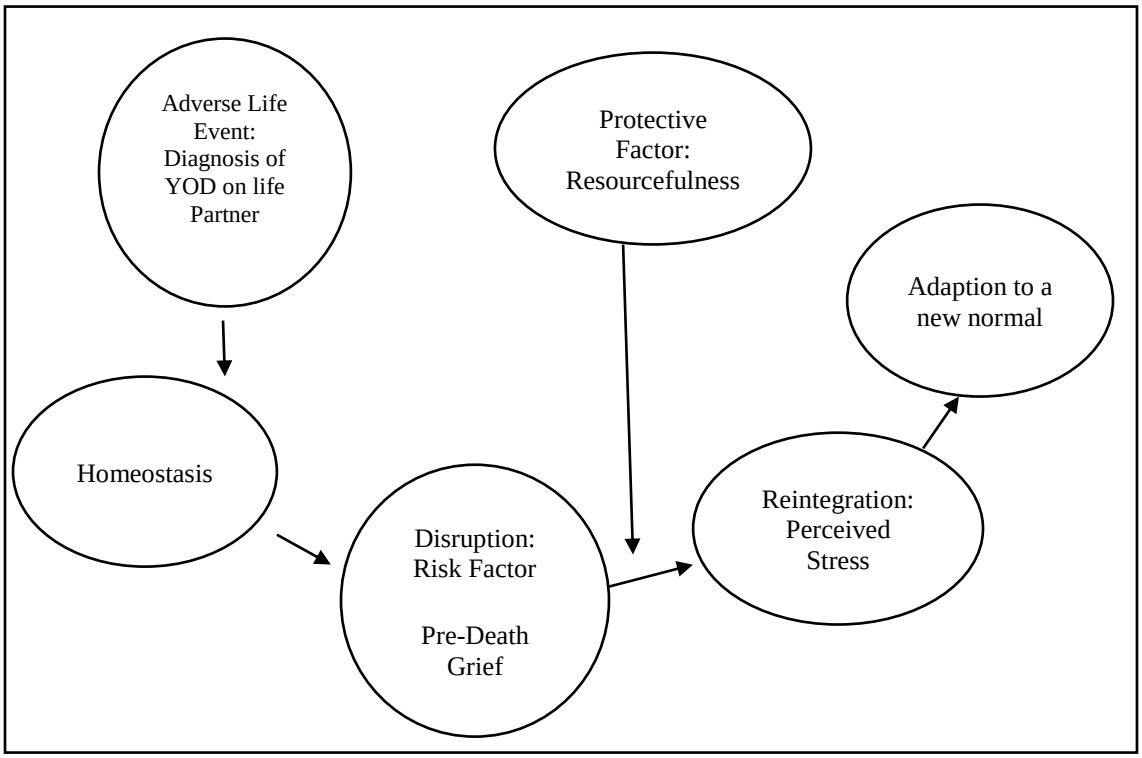


In this study, the adverse life event is the diagnosis of a partner with YOD and the resulting disruption is the experience of pre-death grief that results from the adverse event of the YOD diagnosis. "Disruptions mean that an individual's intact world paradigm is changed and may result in perceived negative or positive outcomes" (Richardson, 2002, p. 311). Pre-death grief changes a previous intact household paradigm for the YOD caregiver into one of living with loss. This disruption is considered a risk factor that is a result from the adverse event of the YOD diagnosis. The caregiver must now cope with and learn to adapt to multifocal losses that continue and progress while adding the caregiver role to their life. The reintegration incorporates how the caregiver perceives the stress of caregiving and the contribution of pre-death grief. This process of reintegration and ultimately adaptation to a new normal may be

affected by the interplay of risk and protective factors. One factor found to act in a protective role with caregivers is resourcefulness (Bekhet, 2013). Figure 2.3 illustrates the relationships tested in this study using Richardson's Resiliency Model.

Figure 2.3

Modified Richardson's resilience theory model



Defining resilience of YOD caregivers. Resilience is a dynamic process that results in positive adaptation after adversity. Adversity involves a "negative life circumstance" (Luther & Cicchetti p. 858) which for this population is the actual diagnosis of YOD. Positive adaptation optimizes wellbeing of the caregiver, the care recipient, and the household with the reintegration of the caregiving role for a partner

diagnosed with YOD (O'Rourke et al., 2010). This concept is fully explored in Chapter 4 as a concept analysis of resilience in caregivers of partners with YOD.

Conceptual, Theoretical and Empirical (CTE) Framework

CTE is often called the theoretical substruction used to identify the constructs and the methodology of the study (Bekhet & Zauszniewski, 2008; Fawcett, 1999). CTE forms the conceptual model that takes a phenomenon from abstract to measurable (Fawcett, 1999). This process describes the characteristics of a phenomenon with the purpose of providing a framework and a perspective of a phenomenon (Fawcett, 1999). For this process, each variable was identified on three levels of conceptual, theoretical, and empirical along with the empirical referent to be utilized in measuring the variables. The conceptual level of the CTE is the most abstract level that provides a frame of reference of the phenomenon for each variable. The theoretical level is the intermediate level of the theory to be tested. The most concrete level is the empirical level which is the measurement of the variable (Fawcett, 1999). Vertical relationships were identified for each variable. Using Resilience Theory, the risk factor was the disruption caused by pre-death grief which was the independent variable in the study. The protective factor was resourcefulness which is a covariant that may moderate the relationship between pre-death grief and the outcome variable. The outcome or dependent variable was a factor that may influence the adaptation process is perceived stress of the caregiver. Figure 2.4 outlines the theoretical substruction of these variables and resilience theory with this study.

Independent variable: Pre-death grief. Pre-death grief was the empirical indicator for this study. The conceptual indicator was loss. Loss is an ambiguous

concept that has multiple applications that imply a separation from something or someone of value (Read, 2005). This separation can be the loss of a loved one, a material loss, or loss of an intangible such as self-esteem or body image (Read, 2005). There are primary losses, which are the actual separation from something or someone of value and secondary losses. Secondary losses occur as a result of the primary loss (Read, 2005). Caregivers of partners with YOD experience multiple losses from financial to social to their relationship with their partner. Grief is the physical, emotional, and psychosocial experience that follows loss (Meuser & Marwit, 2001).

Grief is a human experience that can occur at all ages and across all cultures (Jacobs, 1993). A concept analysis defined grief as "a normal, dynamic, individualized process which pervades every aspect (physical, emotional, social, spiritual) of persons experiencing the loss of a significant other" (Jacobs, 1993, p. 1789). This process is felt in all areas of life from physical to psychosocial to spiritual (Jacobs, 1993). The concept of caregiver grief was originally defined as psychosocial responses to valued loss (Meuser et al., 2004). There are often multiple losses that caregivers of partners with YOD experience. Some losses are financial with the loss of employment for the person diagnosed with YOD as they are no longer able to complete tasks at work to a satisfactory level. Additionally, there may be a potential reduction of employment hours for the caregiver as the caregiver strives to meet the needs of their partner. Other financial losses that may occur are related to the expenses of health care, respite care, and adult day care is utilized. Caring for a partner diagnosed with YOD may also involve loss of companionship and relational deprivation that occurs when the life partner is physically present but not able to be part of the dynamic psychosocial relationship.

Caregiving partners may experience social losses as they often find it difficult to maintain social obligations or are not invited to many social events (Frank, 2007; Noyes et al, 2010; Rosenthal Gelman & Greer, 2011; Svanberg et al., 2010). These losses are operationalized as caregiver grief.

More recently, Lindauer and Harvath (2014) defined the concept of pre-death grief in caregivers of persons diagnosed with dementia as the "emotional and physical response to the perceived loss in a valued care recipient" (p. 2203). The care partner may be experiencing a loss of the partner 'who use to be' even when the partner is still present in a physical sense, which is a specific type of grief known as pre-death grief.

Marwit and Meuser (2005) modified their definition to include pre-death grief to describe the phenomena family members experienced as they watched the social and intellectual death of their loved one due to dementia. Boss (1999) called this pre-death grief experience the 'goodbye without leaving', when a person is physically present yet unable to be psychosocially present. This is a different experience than caring for people with other chronic illnesses (Frank, 2007). Caregivers express elevated levels of stress as a result of this psychosocial absence known as pre-death grief (Frank, 2007). Pre-death grief is an important human response to measure in caregivers of partners diagnosed with YOD since pre-death grief responses are associated with depression and stress which results in physical and psychological illness (Ducharme, et al., 2013; Flynn & Mulcahy, 2013; Lindauer & Harvath, 2014: Roach et al., 2009; Svanberg et al., 2011).

Pre-death grief was measured by the Marwit Meuser Caregiver Grief Inventory Short Form (MM-CGI SF). Thomas M. Meuser, PhD. and Samuel J. Marwit, PhD. of the Alzheimer's disease Research Center in the Department of Neurology in Washington

University's School of Medicine developed a Caregiver Grief Inventory (MM-CGI) to measure current grief in family caregivers of persons diagnosed with dementia (Meuser & Marwit, 2001). Since the experienced grief is being measured when the care recipient is still alive, the tool is measuring what Lindauer and Harvath also termed in 2014 as pre-death grief. Pre-death grief is a current term that was not utilized in 2001 when Meuser and Marwit first published their inventory.

Empirical measure of pre-death grief. Marwit and Meuser developed this tool after review of the literature revealed that caregiver burden, caregiver stress, depression, and coping were addressed in the literature, but there was a lack of information regarding caregivers' loss especially related to the loss of relationship with the person diagnosed with dementia (Meuser & Marwit, 2001). Caregiver grief was found to be quantitatively different from depression (Meuser & Marwit, 2001). The Caregiver Grief Inventory is the first empirical tool measuring dementia caregiver grief (Meuser & Marwit, 2001). The instrument was developed with data from 87 caregivers. The caregivers were recruited through the St. Louis Chapter of the Alzheimer's Association, Washington University's Memory and Aging Project, and through "word of mouth" (Meuser & Marwit, 2001). Caregivers were mailed a packet that included the Anticipatory Grief Scale (AGS), Many Faces of Grief Questionnaire, and a Group Assignment Questionnaire which included a portion of the Clinical Dementia Rating (Meuser & Marwit, 2001). These 87 caregivers then participated in a two-hour focus group that employed a semi-structured interview based off six questions which inquired about loss that occurred since the family members' dementia diagnosis. Focus groups were videotaped with both researchers present at all focus groups.

Quantitative analysis provided descriptive statistics of the sample and correlations between the AGS, the Many Faces of Grief Questionnaire, years of dementia diagnosis, and stage of dementia (Meuser & Marwit, 2001). Qualitative analysis of focus groups revealed rich information of grief themes based on type of caregiver (adult-child versus spouse caregivers) and stage of dementia of family member. These themes and statements were then used in phase two of the instrument development.

Content validity was established through phase one with literature review, questionnaires and focus groups of caregivers of family members diagnosed with dementia. The process of deriving 50 items as noted above occurred through thematic analysis and statistical measures using the experts who are the caregivers. Criterion validity was demonstrated by correlations between the total MM-CGI and the three factors. Marwit and Meuser (2002) reported that the correlation between the total MM-CGI and factor one was .897, factor two was .833, and factor three was .856.

In the second phase of the instrument development, the data was pared down to 184 statements regarding the grief of caregivers of family members diagnosed with dementia and mailed in a questionnaire format to 166 caregiving participants. Participants also completed the AGS, Beck Depression Inventory (BDI), Caregiver Strain Index (CSI), Clinical Dementia Rating Scale (CDRS), Geriatric Depression Scale (GDS), Family Support Questionnaire (FSQ), and Well-Being Scale (WBS). To reduce the 184 items, statistical analysis was done that included correlations and factor analysis with a final version containing 50 items. The 50 items loaded under three factors. These factors are *Personal Sacrifice Burden* which has 18 items, *Heartfelt Sadness and Longing* with 15 items, and *Worry and Isolation* with 17 items (Marwit & Meuser, 2002).

These three factors remain in the MM-CGI SF. Each factor has six items that load on it (Marwit & Meuser, 2005). An intercorrelation matrix demonstrated that validity of the MM-CGI-SF was similar to that of the MM-CGI when compared with BDI, AGS, GDS, CSI, WBS, and the Perceived Social Support Scale (Marwit & Meuser, 2005).

Summary. Pre-death grief is a phenomenon experienced by caregivers of partners diagnosed with YOD. This phenomenon stems from the grief experienced from the multiple losses experienced as a result of the YOD diagnosis. Specifically, it is the type of grief that follows the loss of the psychosocial relationship of a life partner while caring for their physical presence. Pre-death grief can be measured by the MM-CGI SF. The MM-CGI SF was developed to give health care providers a process for rapid screening of dementia caregivers (Marwit & Meuser, 2005). Participant burden was considered when the MM-CGI SF was chosen for this study to measure pre-death grief of partners with YOD. The MM-CGI SF has been used with both adult and adult-children caregivers of those with traditional dementia.

Dependent variable: Perceived stress. The conceptual indicator for this study is life balance. Life balance is the concept that is often referred to in the dyadic relationship between work and life (Drummond et al., 2017). Life balance incorporates the natural conflicts that occur as one juggles all the demands that "pull" on one's time whether these demands are for pleasure or not (Drummond et al., 2017). The result of the struggle to attain a balanced life often results in stress (Drummond et al., 2017).

The theoretical indicator for this study is stress which is often categorized in either a physical response, whether cellular or system focused, or a psychosocial

response, which is based on the individual's perception of an event (Cannon, 1932). Cannon spoke to acute states of arousal which later became the basis of the fight or flight response used in Hans Seyle's General Adaptation Syndrome Model (Videbeck, 2010). Lazarus and Folkman (1984) built a model that then incorporated the psychosocial dimension of stress. This led to Cohen and colleagues (1983) developing a scale to measure perceived stress and address the psychosocial dimension. Caregivers of partners with YOD experience high levels of stress as a result of the disruption in their life balance as they undertake the caregiving role (Flynn & Mulcahy, 2013; Llanque, Savage, Rosenburg, & Caserta, 2016).

The empirical indicator is caregiver perceived stress, which is well documented in the literature and includes caregiver stress as experienced by people caring for persons with dementia. Llanque and colleagues (2016) defined the concept of caregiver stress specifically to dementia caregivers as both a subjective response to the emotional and cognitive aspects of caregiving and as an objective response involving undertaking all the caregiving tasks. One key finding was that caregiving is stressful only when the caregiver perceives it as stressful (Llanque et al., 2016). This finding of perception being important is among the rationale for using the chosen empirical referent.

Empirical measure of perceived stress: Caregiver stress was measured by the Perceived Stress Scale 14 (PSS 14). The Perceived Stress Scale (PSS) was developed in 1983 by Cohen and colleagues based on Lazarus (1966) stress and coping process theory. The PSS was designed to measure an individual's perceptions of experienced stress during the previous month (Cohen et al., 1983). Prior to the PSS, stress had been measured as an objective event that assumed stress events were independent threats

which lacked necessary coping resources (Cohen et al., 1983). Life event scales had been used as these measures of stress. These scales were not chosen for this study due to their lack of inclusion of the subjective appraisal of the caregiving experience. Additionally, life scales measure the number of events, whereas caregiving is a multifaceted, long term experience more so than a single objective event.

Cohen and colleagues (1983) developed the PSS to examine stress globally as an outcome variable that results from an individual's perspective of the event(s). This subjective appraisal has perceived stress as the outcome variable "measuring the experienced level of stress as a function of objective stressful events, coping processes, personality factors." (p. 386). The PSS is not as an objective measure but a subjective appraisal and therefore not a diagnostic tool (Cohen et al., 1983). Perceived stress is a result of how unpredictable, uncontrolled, and overloaded an individual finds life events (Cohen et al., 1983).

The PSS 14 is the initial shortened perceived stress scale developed by Cohen and colleagues (1983). In 1988, Cohen and Williamson also developed two shorter versions: the PSS 10, a ten item self-response questionnaire and the PSS 4, a four item self-response questionnaire. All three versions of the PSS have been widely used and are considered one of the most popular instruments to measure stress (Cohen, Janicki-Deverts, & Miller, 2007).

The PSS 14 items are general in nature and thought to be applicable to most populations and communities (Cohen et al., 2007). Items are written on a junior high school level and are easy to understand (Cohen et al., 1983). The PSS 14 was a better predictor of symptoms experienced and health service utilization within four weeks of

completion of the scale as compared with the other measures. The predictive nature of the PSS 14 decreases after four weeks because the appraisal of stress changes depending on events, the resources available for coping, and other concurring events (Cohen et al., 2007).

Summary. Perceived stress by caregivers of partners of YOD results from the stress that occurs when there is a disruption in life balance. Life balance is disrupted with the adverse event of the diagnosis of YOD of one's life partner. Undertaking a caregiving role can cause a shift in all previous roles resulting in stress. How the caregiver perceives the stress of caregiving for a partner of YOD may influence their adjustment and adaptation to a new normal. This perception of stress is what the PSS 14 is designed to measure.

The PSS 14 has been used with a variety of populations and does not seem to be influenced by gender or age (Cohen et al., 1983; Lee 2012). Some of the populations it has been used with include college students, people in smoking cessation programs, people with diabetes with poor blood sugar control, people who suffer more colds, people with depression, and people with ill children (Cohen et al., 2007; Lee, 2012). The PSS scales have been translated into different 25 languages including Chinese, Portuguese, Greek, Italian, German, Danish, Norwegian, and Spanish (Cohen's Laboratory for Stress, Immunity and Disease, 2012; Lee, 2012). This instrument has demonstrated usefulness with individual perceptions of stress over the previous month. Pre-death grief is a subjective and individualized experience. Therefore, the PSS 14 was chosen since this instrument incorporates the caregiver perceptions of the stressor that is individually experienced in their daily life over the past month.

Moderator: Resourcefulness. The conceptual indicator for resourcefulness for this study is self-help and help-seeking behaviors. This references the ability to solve problems through self-help which is the ability to maintain independence through adversity, and help-seeking, which is the ability to seek and obtain help from others when necessary (Zauszniewski et al., 2006). The ability to self-help and seek-help are behaviors that are important for managing stressful situations and cope with adverse events (Zauszniewski et al., 2006).

The behaviors of self-help and to seek-help are two theoretically related constructs to resourcefulness which is the theoretical indicator of this study (Zauszniewski et al., 2006). Rosenbaum (1983) described resourcefulness as having four factors. These four factors include (1) positive statements, (2) ability to problem solve, (3) ability to delay gratification, and (4) perceived self-efficacy. Zauszniewski and colleagues (2006) later developed the Theory of Resourcefulness and Quality of Life. This theory evolved from Rosenbaum's original theory. Resourcefulness is the ability to problem solve through self-help (personal resourcefulness) and to seek help from others (social resourcefulness) and in adverse situations which enhances resilience and promotes generalized well-being (Zauszniewski et al., 2009). Zauszniewski and colleagues (2006) states that both personal and social resourcefulness skills are theoretically related yet have different foci. Personal resourcefulness was defined by Rosenbaum (1990) as learned resourcefulness and incorporated skills to maintain independence in the presence of adversity (Zauszniewski et al., 2006). Social resourcefulness is an external process of seeking assistance from other individuals or agencies when one is no longer able to successfully manage on one's own (Zauszniewski et al., 2006). Social resourcefulness

skills involve seeking and asking family, friends or professional for help. Both personal and social resourcefulness skills are important for optimizing well-being, health promotion, and health maintenance.

These abilities to solve problems with self-help in personal resourcefulness and to seek help from others as in social resourcefulness are the resourcefulness skills that form the empirical indicator for this study. Zauszniewski, Lekhak, Yolpant and Morris (2016) found in women caregivers of elders with dementia low resourcefulness scores were a risk factor for their psychosocial well-being. The majority of participants in the study by Zauszniewski and colleagues (2016) scored low on the resourcefulness scale demonstrating low resourcefulness skills prior to two resourcefulness training interventions of journaling and voice recording. Once these participants had resourcefulness training, their resourcefulness skills increased suggesting that resourcefulness training is needed and may be suitable to caregivers. It is recommended that future studies should evaluate resourcefulness training on caregiver health (Zauszniewski et al., 2016). Wawrziczny and colleagues (2017) found that caregivers of YOD experience frustration in their abilities to navigate the system to locate resources and services for their partner and for themselves. The ability to seek help from others is social resourcefulness which is one component of resourcefulness. Resourcefulness skills are a protective factor and can enhance adaptation and well-being (Zauszniewski et al., 2006).

Empirical measures for resourcefulness skills. Zauszniewski developed the Resourcefulness Scale (RS) to assess both personal and social resourcefulness with two different subscales in one tool to provide a more complete picture of an individual's

resourcefulness skills (Zauszniewski et al., 2006). The tool was first used in two studies with older adults from retirement communities for a total sample of 451 people. Even though personal and social resourcefulness are theoretically related Zauszniewski et al. (2006) used correlations with the Rosenbaum's Self-Control Schedule and Zauszniewski's Help-Seeking Resourcefulness Scale to determine if the both constructs could be measured in the same scale (Zauszniewski et al., 2006). With acceptable levels of internal consistency and high levels of correlations, both personal and social resourcefulness skills could be measured on one scale.

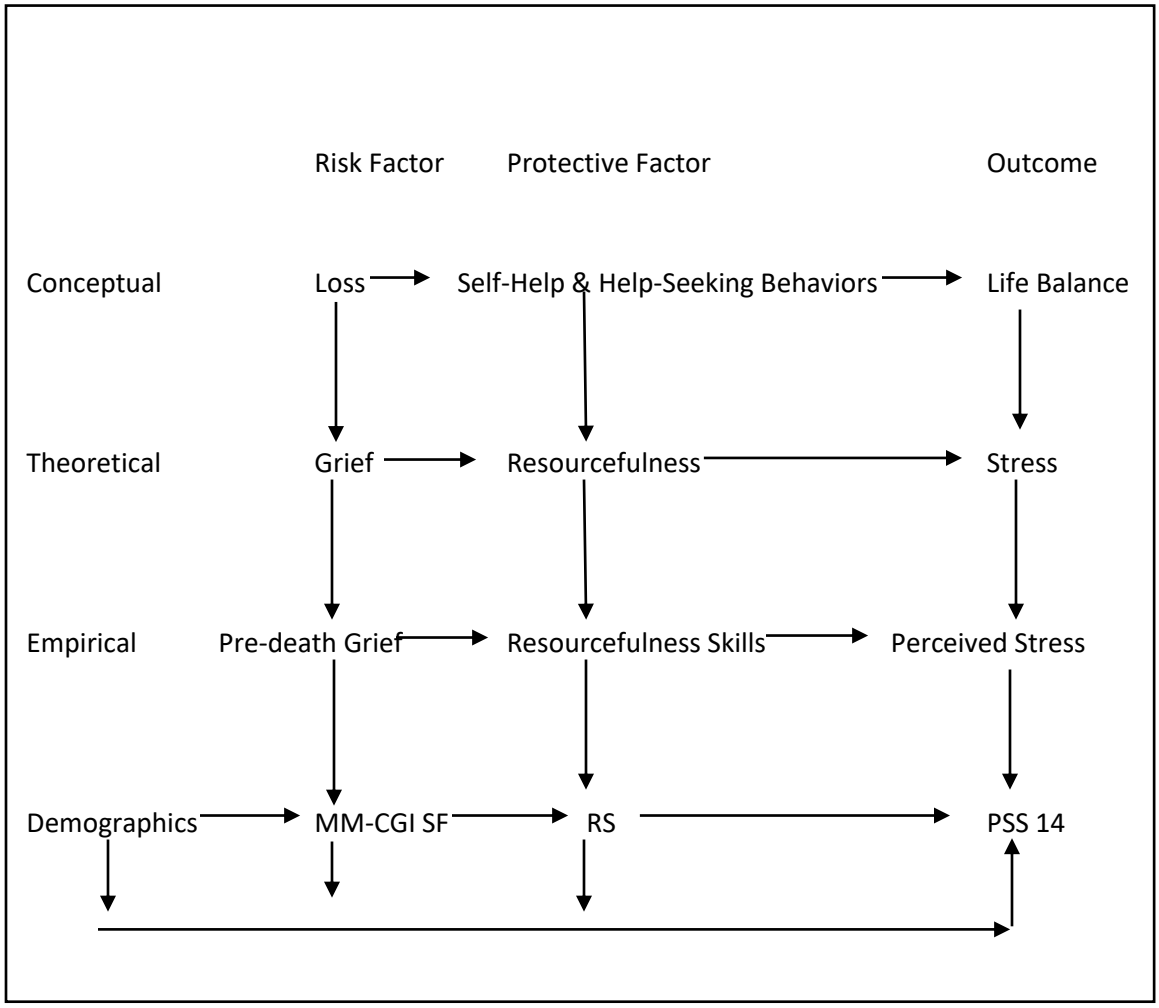
Psychometric testing of the RS split the sample into two groups; one for instrument development and one for testing. First internal consistency and construct validity were evaluated for 36 items in the personal resourcefulness subscale. After item-to-total analysis, 19 items were dropped and 16 remained for factor analysis. These 16 items had a Cronbach's α of .84 and could be forced into a single factor with factor loadings exceeding the .32 benchmark and explaining 30% of the variance. The 12-item social resourcefulness subscale was then evaluated. This subscale had a Cronbach's α of .8 and item-to-total correlations exceeding the .3 benchmark. Factor analysis forced items into a single factor with factor loadings exceeding the .32 benchmark and explaining 26% of the variance (Zauszniewski et al., 2006).

Summary. Resourcefulness skills are a protective factor that enhance resilience. These skills are beneficial to caregivers of partners diagnosed with YOD for solving problems that develop as a result of caregiving and for seeking help when needed. The RS measures both personal and social resourcefulness. Populations with whom the RS has been used include female relatives of mentally ill adults (Zauszniewski et al., 2009),

female caregivers of elders with dementia (Zauszniewski, Lekhak, Yolpant, & Morris, 2015), and caregivers of persons with dementia (Bekhet, 2013).

Figure 2.4

Theoretical substruction with variables



Literature search

Search strategy: Databases searched include Cumulative Index of Nursing and Allied Health Literature (CINAHL) from EBSCO, ProQuest, PsychInfo and PubMed

from the National Institutes of Health. Keywords used include *young onset dementia, early onset dementia, young onset Alzheimer's disease, early onset Alzheimer's disease, pre-death grief, caregiver grief, and resourcefulness.* Table 2.1 lists combinations of search terms with results.

Table 2.1

Search term combinations

Search Term Combinations	**Results**
Young Onset Dementia	74
Caregiver	29519
Grief	6795
YOD & Caregiver	9
YOD & Caregiver & Grief	4
Caregiver & Resourcefulness	30 5 relating to dementia
All other combinations	0

Inclusion criteria comprised full articles in peer reviewed journals written in English since 2000. Table 2.2 lists inclusion and exclusion criteria.

Table 2.*2*

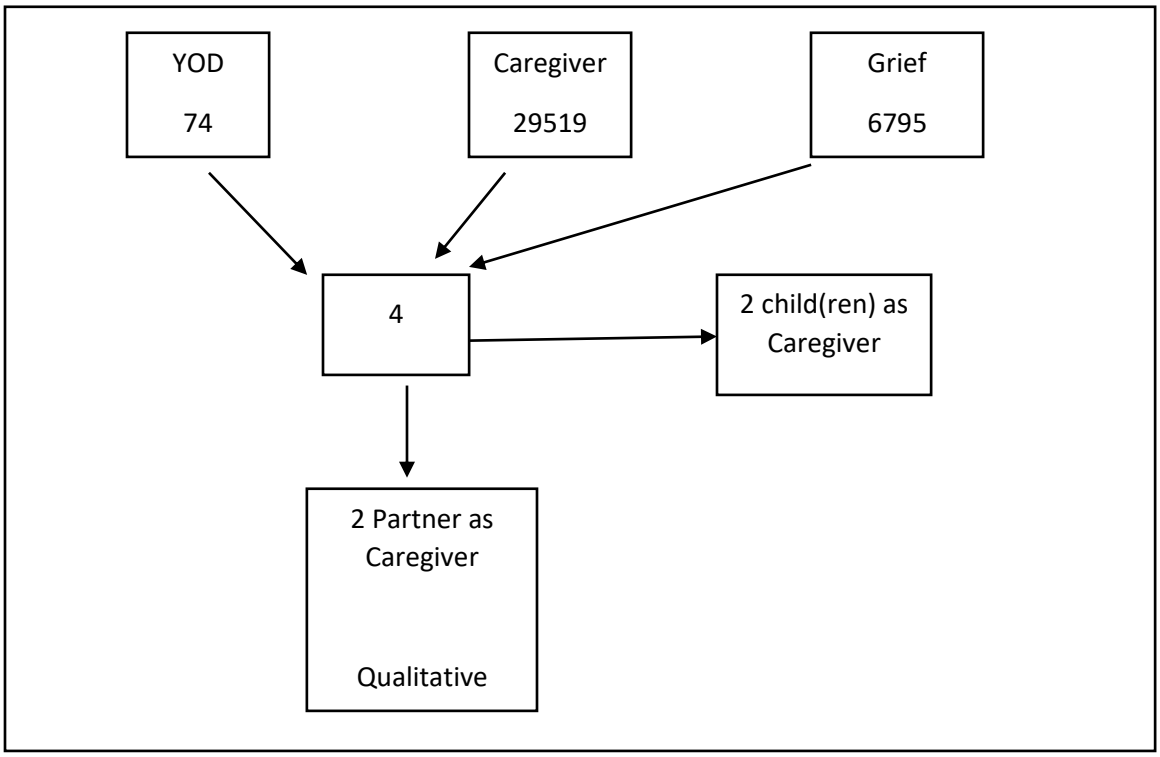
Inclusion/exclusion criteria

Inclusion	**Exclusion**
Peer Reviewed Journals	Dissertations
English	Child(ren) as caregivers
2000-2017	Pre- 2000
Full Article	

Results of literature search: The initial search produced 74 articles on YOD, 29519 on caregivers and 6795 on grief. Article titles were evaluated for the population composition of young onset dementia and search terms were combined with 'and' resulting in four articles. Further appraisal of articles for the concept of pre-death grief yielded two articles that addressed pre-death grief and YOD caregiving. Figure 2.5 is a flow diagram of the literature search.

Figure 2.5

Literature search diagram



Synthesis of Evidence:

In recent years, peer reviewed articles on YOD and YOD caregiving increased. This was evident in a simple search which found 74 articles between 2002-2017 on YOD with 54 of those in the past 5 years and 30 of those articles being published in the last 18 months. The literature on YOD caregivers was confined to seven qualitative and two quantitative articles. Flynn and Mulcahy (2013) qualitative study identified four themes: (1) diagnostic difficulties, (2) impact of caregiving, (3) relationship changes, and (4) lack of resources. The third theme of relationship changes begun to note that there was an identified change in the relationship, but this theme lacked the specifics that would meet the criteria of an identified loss. Similarly, in a qualitative literature review, Spreadbury

and Kipps (2017) recognized that caregivers do experience grief through multiple perceived losses. However, this statement was in reference to the article by Ducharme et al. (2013), which was one of the two articles located in the literature search above. Remaining articles identified results of caregiving such as burden related to the development of depression (Armani et al., 2013; Kaiser & Panegyres, 2007; Werner et al., 2009), diagnostic difficulties (Armani et al., 2013; Millenaar et al., 2016; Svanberg et al., 2011), lack of age appropriate services and resources (Armani et al., 2013; Gibson et al., 2014; Millenaar et al., 2016; Svanberg et al., 2011; Werner et al., 2009) and that there were unique challenges which either were different or were perceived to be more stressful for caregivers of partners with YOD than with other forms of dementia (Armani et al., 2013; Gibson et al., 2014; Millenaar et al., 2016). Werner et al. (2009) found in addition to higher levels of perceived stress amongst caregivers of partners with YOD, these caregivers also often had greater financial concerns. As future research is conducted relating to YOD and caregiving for YOD further development of knowledge will occur.

Similarly, knowledge development was only beginning to explore this relatively new concept of pre-death grief as evidenced by only two articles addressing caregivers of partners with YOD and pre-death grief. Table 2.3 summarized the two articles. Specifically related to YOD, the literature supported that the partner was most often the primary caregiver. Children were often identified as secondary caregivers that frequently provided care such as the tasks of feeding and bathing when needed to care for their parent. There were identified differences in care needed for families with YOD. These identified differences were primarily related to the age of the family members and the

developmental stage of the family. Most resources that were available for people with dementia were designed for people with traditional dementia that occurs after the age of 65. Resources and programming were often found not relevant to YOD couples.

Pre-death grief was found to be different from anticipatory grief since the loss that was being experienced was a psychosocial loss while the physical existence was still present (Lindauer & Harvath, 2014; Marwit & Meuser, 2005). Loss experienced by partners of YOD was multifactorial with losses occurring in role, financial, future plans, psychosocial areas of partnership, relationship, and socialization while physical presence of the partner remains (Cabote, Bramble & McCann, 2015; Ducharme et al., 2013; Lindauer & Harvath, 2014; Marwit & Meuser, 2005). Pre-death grief in caregivers of partners with YOD experienced the loss of the reciprocal relationship (Lindauer & Harvath, 2014; Marwit & Meuser, 2005). This loss of the reciprocal relationship was associated with sadness, loneliness, and frustration (Flynn & Mulcahy, 2013).

In the first article Ducharme et al. (2013), found six themes specific to caregivers of partners with YOD in a qualitative phenomenological study. Ducharme et al. (2013) referred to the research of caregivers of partners with YOD currently being in an "embryonic state" (p. 635). Semi-structured interviews were employed with 12 caregivers of partners with YOD located in Canada. Of these six themes identified, three were specific to pre-death grief. These themes included (1) loss of partner, & married life & 'normal' life, (2) loss of relationship, spouse role & social time, and (3) loss of previous roles, identity & future plans. Ducharme et al. (2013) also discussed the loss of "reciprocal exchanges" and loss of "normal life" that was common for partners at that stage of family development (p. 638). Ducharme et al. (2013) found that a dyadic

approach to education, interventions, support systems and resources be considered for both caregiver and care recipient based on their unique needs related to their age. Additional support systems would also be beneficial for the entire family including support for children still residing in the house.

The second article by Lockeridge and Simpson (2012), which was also qualitative, found one of four themes relating to the concept of pre-death grief as experienced by caregivers of partners with YOD. Lockeridge and Simpson (2012) aimed to explore the lived experience of the caregivers of partners with YOD located in the United Kingdom. Semi-structured interviews were utilized with the six participants who were the primary caregivers for their partners with YOD in this interpretative phenomenological study. The theme that identified adaptation to loss with two major subthemes of (1) the continual daily loss in the partner's abilities as the disease progressed and (2) the loss of future plans and the continual loss as experienced in the present that occurs with the slow progression of YOD disease process (Lockeridge & Simpson, 2012). Lockeridge and Simpson (2012) also recommended that support services and resources need to be tailored for YOD that are both practical and age appropriate.

Both articles discussed the difficulties the caregiving partners experienced with the multiple losses that occur once their partner was diagnosed with YOD. These losses were operationalized as the concept of pre-death grief. These multiple losses were persistent with a continual evolution of new loss as the disease process progresses. Caregivers of partners with YOD continued to attempt to adapt to this constant deterioration of their partner as losses (social, personal, relationship, future plans, and financial) continued to accumulate increasing caregiver stress from undertaking this

caregiving role. With the concept of pre-death grief in the "embryonic" stages of concept development and the population of caregivers of partner with YOD was a relatively recent population of interest, current studies that address predeath grief in caregivers of YOD were limited.

In a systematic review, Richardson and colleagues (2016) came to a similar conclusion in that there was a "significant limitation of available research" (p.1448) related to YOD caregiving which may affect long term impact of any interventions with implications effecting the whole family. In reviews of the literature relating to YOD caregiving that were conducted by Cabote and colleagues. (2015), Richardson and colleagues (2016) and van Vliet and colleagues (2010), the theme of loss related to relationships, finances/employment, and socialization was present. Additionally, differences in caregiving with traditional dementia versus YOD were noted in those areas. These differences resulted in high perceptions of stress and burden among caregivers of partners with YOD (van Vliet et al., 2010). Ducharme's et al. (2014) study confirmed the unmet needs of YOD caregivers included few interventions, services, and resources to address these needs of loss, which contributed to stress and burden. Current literature supported the need for additional studies related to caregiving for partners with YOD and pre-death grief. Additionally, these studies were conducted in Canada (Ducharme et al., 2013) and in the United Kingdom (Lockeridge & Simpson, 2012). There were limited studies on not only YOD, but also on pre-death grief for caregivers of partners of YOD being conducted in the United States.

Table 2.3

Summary of articles

1st Author **Date** **Location**	**Evidence** **Type**	**Sample**	**Findings**	**Evidence Level***
Ducharme et al. 2013 Canada	Qualitative Phenomen-ological Semi-structured interviews	12 spouses of YOD 8 women 4 men Average age 55 with SD 6.9	*6 themes* 1. Difficulty managing behaviors 2. Long quest for diagnosis 3. Denial of diagnosis 4. Grief for loss of married life 5. Caregiver role 6. Difficulty planning for future	6 – Single descriptive or qualitative study
Lockeridge & Simpson 2012 UK	Qualitative Phenomen-ological Semi-structured interviews	6 spouses of YOD 4 current caregiver 2 with decease spouse	*4 themes* 1. This is not happening/denial as coping 2. Stigma 3. Struggle and fight to control events and emotions 4. Adaption to loss	6 – Single descriptive or qualitative study

*Evidence level above is rating system pyramid from Melnyk, B.M. and Fineout-Overholt, E. (2011). *Evidence-based practice in nursing & healthcare: A guide to best practice.* Pyramid rating scale is 1-7 with 1 as strongest and 7 as weakest evidence.

***Grief in dementia caregivers*.** Pre-death grief was a relatively new concept that was unique and applied to only a few diagnoses such as YOD as it considered the loss that occurs while caregiving for a physical presence when the psychosocial presence no longer exists (Lindauer & Harvath, 2014). Since the literature search yielded only two articles related to pre-death grief and caregiving for a partner with YOD and both were

conducted outside of the United States, an additional search was undertaken to further develop what is known regarding pre-death grief and dementia caregiving.

The databases that were searched were identical to the previously listed ones. Search terms employed were *grief, pre-death grief, dementia, Alzheimer's disease, and caregiver.* Inclusion criteria used the same date range of 2000-present to obtain most current knowledge. Remaining inclusion and exclusion parameters were the same as previously noted. Figure 2.6 illustrates the article selection process.

This concept of pre-death grief was spearheaded by Meuser and Marwit (2001) as they developed the instrument of Caregiver Grief Inventory in response to themes from previous studies examining caregiving for persons diagnosed with Alzheimer's disease. Meuser and Marwit noted that themes of loss and grief continued to emerge as studies were conducted with these caregivers.

Synthesis of the current literature found grief themes that often mirrored what was found with YOD caregivers. Some of the commonalities between traditional dementia caregivers and YOD caregivers included loss of relationship and ambiguous loss (Betts & Sanders, 2004; Frank, 2007; Shuter et al., 2013). Frank (2007) also found that caregivers experienced high levels of grief if they lacked a support system. The loss of relationship for caregivers of partners with dementia including YOD was associated with high levels of grief.

Since there existed more studies with traditional dementias, the concept of grief and traditional dementia caregiving had more data than YOD caregiving. Betts and Sanders (2004), Ott, Sanders, & Kelber, (2007) and Wachol-Biedermann and colleagues

(2014) found that the stage of dementia of the care recipient was associated with the level of grief of the caregiver. The later and more severe stages of dementia of the care recipient found that caregivers had higher levels of grief. Ott and colleagues (2007) also found that high levels of grief was associated with depression and negative mental health outcomes. Location of residents for the care recipient had an influence on grief experienced by the caregiver. When the care recipient lived at home, 59.7% of the variance in caregiver grief was explained demonstrating that residence of care recipient impacts caregiver grief (Ott et al., 2007). People diagnosed with YOD tended to remain in their home longer than those with traditional dementia which may explain why caregivers of YOD perceived high levels of stress (Ott et al., 2007; van Vliet et al., 2010).

Both Noyes and colleagues (2010) and Blandin and Pepin (2015) developed models of the grief experience in caregivers for persons with dementia. Noyes and colleagues (2010) model was based on the Stress Process model from Pearlin. This linear process model evaluated the contextual losses experienced by caregivers of persons with dementia, caregivers' appraisal of the significance of these losses and the resulting expressions of grief and stress. Whereas, the Blandin and Pepin (2015) Dementia Grief Model depicted a cyclic process of states of grief as experienced by dementia caregivers. Both models illustrated a grief process specific for caregivers of persons with dementia.

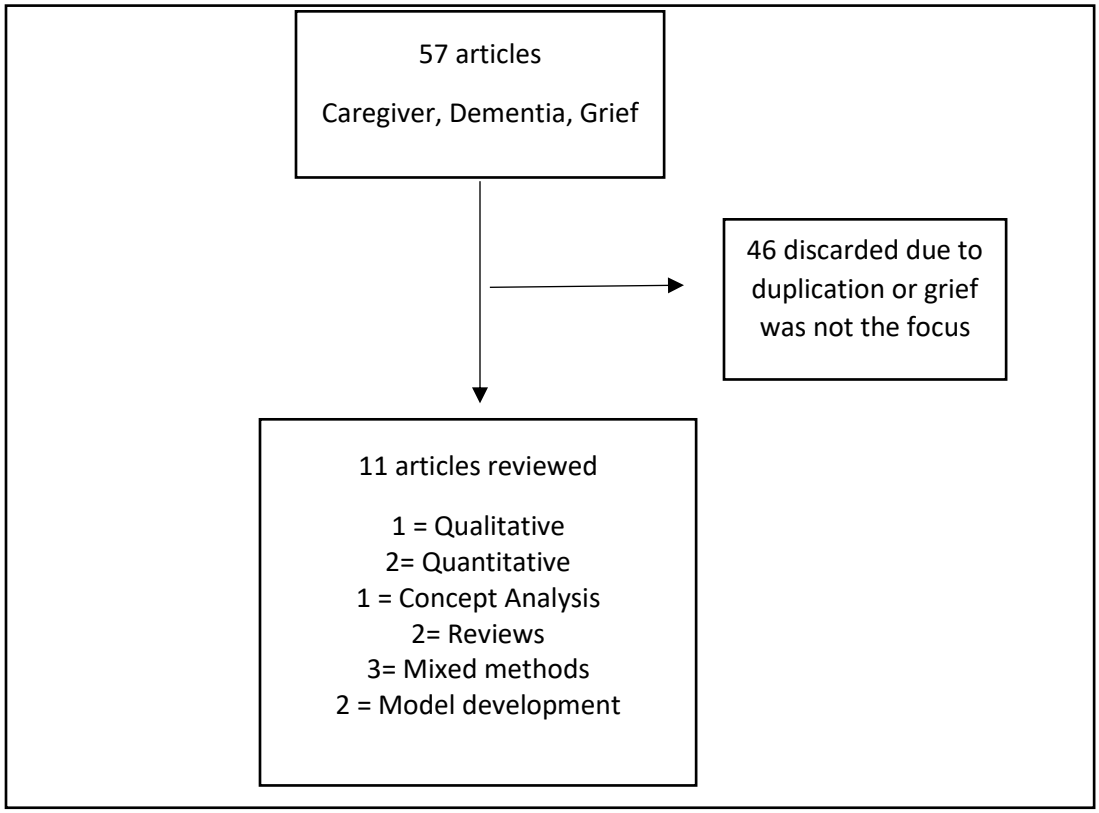
These articles referred to the grief that was experienced by caregivers of persons with dementia as the psychosocial loss prior to physical loss of the care recipient. In this regard, Lindauer and Harvath (2014) presented a concept analysis of pre-death grief. In this concept analysis, pre-death grief was defined as:

> Pre-death grief in the context of dementia family caregiving is the caregiver's emotional and physical response to the perceived losses in a valued care recipient. Family caregivers experience a variety of emotions (e.g. sorrow, anger, yearning, and acceptance) that can wax and wane over the course of a dementing disease, from diagnosis to the end of life. The pre-death grief is due to (a) care recipient psychological death, which is asynchronous with physical death; (b) a lengthy and uncertain disease trajectory; (c) compromised communication between the person with dementia and the family caregiver; (d) changes in relationship quality, family roles and caregiver freedom. Pre-death grief can contribute to caregiver burden, depression, and maladaptive coping (Lindauer & Harvath, 2014, p. 2203).

The concept of pre-death grief addressed the compounded, serial losses as experienced by caregivers of persons with dementia.

Figure 2.6

Expanded search of pre-death grief and dementia caregiving



Resourcefulness in dementia caregivers. A literature search of the above-mentioned databases was completed for resourcefulness in dementia caregivers as there were no articles found on resourcefulness and YOD caregivers. Inclusion criteria was peer-reviewed journals and articles from 2000 to present in English with resourcefulness and dementia caregiving as major themes in the article. Of the 264 articles on resourcefulness only five met all inclusion criteria. Three of the articles addressed the need for resourcefulness training in dementia caregivers. Using the resourcefulness scale, Zauszniewski and colleagues (2015) found in a sample size of 126 female caregivers that 75% had scores that indicated a moderate to high need for resourcefulness training. Additionally, participants with scores that indicated low levels of resourcefulness had scores on the Center for Epidemiological Studies-Depression Scale and the PSS 14 that indicated higher levels of depressive symptoms and higher levels of stress than participants whose scores indicated high levels of resourcefulness. In two other studies by Zauszniewski and colleagues (2016), results indicated that caregivers of persons with dementia could benefit from resourcefulness skill training to decrease caregiver stress using two different methods of journaling and voice recording. Results indicated that caregivers having a choice in preferred option for building resourcefulness skills had better success with building these skills. Bekhet (2013) found in 80 dementia caregivers that positive cognitions mediated the relationship between caregiver burden and resourcefulness that indicated that positive cognition interventions may benefit resourcefulness skills building in dementia caregivers. In a descriptive, cross-sectional study with 73 dementia caregivers, Bekhet (2015) found that Caucasian Americans reported greater burden, anxiety and depression than African American caregivers.

Whereas, African American caregivers reported greater resourcefulness, positive thinking and overall psychological well-being. For both populations, caregivers with greater social resourcefulness had scores indicating greater psychological well-being. All articles indicated that caregivers of persons with dementia experience high levels of burden and stress. Resourcefulness skill building was associated with a decrease in caregiver burden and stress in these five studies. There were no studies that assessed the specific population of YOD caregivers.

Gaps in literature. The most notable gap was the limited research on not only the population of caregivers of YOD, but also on the concept of the pre-death grief experience. The synthesis of current literature on pre-death grief as experienced by caregivers of partners with YOD supports the experience of multiple loss and limited support for these caregivers.

The impact of pre-death grief has not been fully studied for an association to caregiver stress or related to caregivers of partners with YOD. Understanding the pre-death grief experience of caregivers of partners diagnosed with YOD and any associations to caregiver stress enables the future development of interventions and services with a goal of decreasing caregiver morbidity and mortality and increasing quality of life. The limited number of studies demonstrated need for further research on loss as experienced by caregivers of partners with YOD. Quantitative studies are needed to further understand loss experienced by caregivers of partners with YOD. Additionally, it is noted that there are few studies done in the United States with pre-death grief and young onset dementia caregivers. The two studies found took place in Canada and the United Kingdom.

Assumptions of study

Assumptions for this study included that YOD was irreversible and progressive in nature. To date there is no known cure for YOD. Additionally, this study assumed that the caregiver and the care recipient had a relationship of mutual support. The caregiver was assumed to desire to provide optimal care to their partner diagnosed with YOD.

Aims/Hypotheses

The specific aims, research questions, and hypotheses of this study were:

Aim 1: To examine the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis1: Caregiver pre-death grief has a positive association with caregiver perceived stress in caregivers of a partner with YOD.

Aim 2: To determine whether personal and/or social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2a: Personal resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2b: Social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Summary

YOD is the diagnosis of dementia prior to the age of 65. The most common caregiver for a person with YOD is their life partner. The caregiver stress experienced by caregivers of a partner with YOD is different than traditional dementia relating to the life stage of the family. Caregivers of partners with YOD experience multiple losses including; financial losses, social losses, loss of future plans and loss of the reciprocal relationship one has with their spouse. These losses are operationalized as pre-death grief as the partner is still physically present, but the psychosocial relationship is gone. This pre-death grief is unique to YOD, dementia and possibly traumatic brain injuries.

Using Resilience Theory, this study assessed the relationship of pre-death grief on perceived stress of the caregiving partner. Additionally, this study evaluated a possible moderating role of resourcefulness on this relationship. Resilience theory discusses the interplay of risk factors and protective factors on adaptation after an adverse event. The diagnosis of a partner with YOD was an adverse event. Resourcefulness may be a protective factor that moderates the risk factor of pre-death grief on perceived stress of the caregiver. The amount of perceived stress may be influential on caregiver adaptation to a new normal after the YOD diagnosis.

Current literature was limited in studies on YOD, caregiving for a partner diagnosed with YOD, and the pre-death grief experience. The few studies that existed were qualitative in nature and examined the YOD caregiving experience. To date, no studies have assessed the moderating role of resourcefulness on perceived stress as proposed in this study. Assessing the relationship between pre-death grief, resourcefulness, and perceived stress provides direction for future development of

tailored interventions to address caregivers' pre-death grief which might impact their psychological well-being and the care provided to their partners. Additionally, as science is continuing to expand into the cellular level, there is an emerging study of the neurobiological basis to resilience (Pfau & Russo, 2015) and of the consequences of dementia caregiving (Fonareva & Oken, 2015). Future studies could include evaluating an individual's perception of pre-death grief, stress, and/or well-being and match these findings with neurobiological markers.

CHAPTER III
Research Design and Method

The methodology of the study is discussed in this chapter. More specifically, the chapter includes a description of the research design and sampling details, including sample specifications, inclusion and exclusion criteria, and sample size determination based on power analysis. The chapter also includes the data collection procedures, the issues of measurement and instrumentation, protection of human rights, data management, and finally, a description and discussion of the analysis.

Purpose

The purpose of this study was to determine if a relationship existed between caregiver's pre-death grief and caregiver's perceived stress. Additionally, this study explored possible moderating effects of resourcefulness, both personal and social, on any potential relationship between pre-death grief and perceived stress of a caregiver of a partner diagnosed with YOD.

Research Design

This cross-sectional, correlational study evaluates the relationships between pre-death grief, perceived stress, and resourcefulness. Specifically, the moderating effect of personal and social resourcefulness on the relationship between pre-death grief and perceived stress is examined. The study variables were selected based on the literature review regarding themes expressed by caregivers of partners with YOD (Cabote et al., 2015; Ducharme et al., 2013; Flynn & Mulcahy, 2013; Lockeridge & Simpson, 2012;

Spreadbury & Kipps, 2017) and on the literature of resilience for caregivers of dementia which found resourcefulness is often a protective factor for these caregivers (Bekhet 2013, Bekhet, 2015; Zauszniewski et al., 2009). To date, no studies have been found that explore the relationship among the proposed study variables. Therefore, the findings from this study contribute to nursing knowledge regarding a vulnerable population and the potential risk factors that may predispose this population to maladaptation including increased morbidity and mortality risks.

A cross-sectional, correlational design was used to answer the research questions. This design was appropriate for this study as it allowed the researcher to examine multiple variables measured at one point in time without any experimental manipulation of independent variables (Field, 2013). The advantage of this design includes illustrating relationships that may occur between the variables of pre-death grief and perceived stress of a caregiver for a partner with YOD (Polit & Beck, 2017). Moreover, the study determined whether this relationship was moderated by the variable of resourcefulness, including both aspects of personal and social resourcefulness. The design of this study allowed previous identified themes from qualitative studies (Ducharme et al., 2013; Lockeridge & Simpson, 2012) to be measured using instruments previously developed and used with the population of interest. This positivist study is grounded in the objective measurement of the variables of pre-death grief, perceived stress and resourcefulness on a sample of caregivers of a partner diagnosed with YOD (Polit & Beck, 2017). By having a single survey and gathering data from one point in time, there was a reduced risk of missing data or participant fatigue and drop out in this initial examination of the relationship between pre-death grief and perceived stress in caregivers

of partners with YOD (Polit & Beck, 2017). A limitation of a correlation study design was that it is not designed to determine causality as evidenced by one variable causing a change in the other variable (Fields, 2013).

Sampling Details

Sample specification: A convenience sample was obtained by recruiting potential subjects via fliers at and a newsletter from the Alzheimer's Association office in south eastern Wisconsin, emails and fliers to Alzheimer's Associations through Wisconsin and the United States, Departments of Aging and Disability in the State of Wisconsin, University of Kansas Alzheimer's Disease Center, Dominantly Inherited Alzheimer Network (DIAN) Project Expanded Registry and word of mouth until the desired sample size is reached. A convenience sample allows for the gathering of participants who possess the characteristics necessary for a study, which was to be the primary caregiver for a partner diagnosed with YOD (Polit & Beck, 2017). The benefit of using convenience sampling was that data can be collected on a targeted population in a cost-effective manner. (Polit & Beck, 2017).

Sample size. Determination of the sample size depends on the number and type of variables, as well as the method of planned statistical analysis (Polit & Beck, 2017). The most effective method in determining the sample size is through power analysis (Polit & Beck, 2017). In determining sample size by power analysis, the significance level (α), power (one minus β), and effect size must be estimated. Power, sample size, and effect size are all linked (Fields, 2013). Effect size also depends on the method of analysis used.

The significance level represents the probability of rejecting the null hypothesis if it is true (Field, 2013). This is known as a Type I error. The significance level is denoted by α. For this study, the α was set at 0.05, which accepts that there was a 5% chance of inappropriately rejecting the null hypothesis of no relationship between pre-death grief and perceived stress for caregivers of partners with YOD.

The power of the test is the probability of finding an effect assuming an effect exists between variables. Type II errors occur when the null hypothesis is accepted, stating there is no relationship, when it should be rejected, as there is an actual relationship (Field, 2013). Power is the ability to find a relationship and is represented by $1 - \beta$. Cohen and Williamson (1988) recommends β is set at 0.2 resulting in a power of .8. Therefore, for this study, the power was set at .8 denoting an 80% probability of detecting a relationship between pre-death grief and perceived stress among caregivers of partners with YOD.

Effect size measures the influence of the independent variable on the dependent variable or the amount of influence of pre-death grief on caregiver perceived stress. The effect size used is f^2 (Cohen, 1992), which represents an increase in R^2, meaning an increase in the model's ability to increase its predictive accuracy. Following Cohen's (1992) criteria, a small to medium effect size was used of .1, which represents a model where the moderation accounts for 10% of the variance of the outcome. Sample size can be calculated using $\alpha = .05$ and $\beta = .8$ with a $f^2 = .1$ for a small to medium effect size. Sample size was then calculated with G*Power (Faul, Erdfelder, Lang & Buchner, 2007) to determine how many participants were necessary to detect a small to medium effect size of the moderation of resourcefulness for the relation between pre-death grief and

perceived stress in caregivers of YOD. For these conditions, the required sample size was $N = 100$.

Subjects. A convenience sample of 104 participants was recruited from the Alzheimer's Associations through Wisconsin and the United States, Departments of Aging and Disability in the State of Wisconsin, University of Kansas Alzheimer's Disease Center, DIAN Project Expanded Registry and word of mouth. Inclusion criterion for participation in this study was being the primary caregiver for a partner diagnosed with YOD, defined as dementia diagnosis prior to the age of 65. Participants must also be at least 18 years of age, understand and be able to communicate effectively in English, and be able to effectively navigate a survey on a computer to be included in this study.

Recruitment procedure. Participants were recruited via emails from Alzheimer's Associations through Wisconsin and the United States, Departments of Aging and Disability in the State of Wisconsin, University of Kansas Alzheimer's Disease Center, DIAN Project Expanded Registry that contained an IRB pre-approved flier. Participants were also recruited via word of mouth and a hand-out of the IRB pre-approved flier. Fliers contained a link to the survey through the online platform Qualtrics. Participants accessed the study via a computer with a link to the surveys through an online platform of Qualtrics. The initial screen provided participants with background information for the study, resources for participants if needed, and an agreement for their informed consent to participate or opt out of survey. Additional screens link to survey instruments. At the completion of the surveys, participants were thanked for their participation and linked to a $20.00 gift card.

Measures

Measures that were used in this study were selected based on evidence of psychometric properties, including reliability and validity. The numbers of items for each instrument were taken into consideration to minimize missing data and subject burden. These self-report surveys were measures for the variables that were chosen to align with the conceptual definition of the variable as demonstrated in Table 3.1. Demographic data was obtained to explore any possible effects of caregiver age, gender, race/ethnicity, education level and socioeconomic status on the relationship between pre-death grief, and resourcefulness.

Independent variable: Pre-death grief. Pre-death grief was measured using the Marwit Meuser Caregiver Grief Inventory Short Form (MM-CGI SF), which has reported acceptable inter-item correlation as demonstrated by a Cronbach's α of .96 (Marwit & Meuser, 2005). The MM-CGI SF was developed using "an inter-correlation matrix technique" which "compared scores on items within as well as between factors and to arrive at those which most robustly portrayed the nature of the 50 item Marwit Meuser Caregiver Grief Inventory" which has demonstrated strong reliability and validity (Marwit & Meuser, 2005, p. 202). The MM-CGI SF has 18 items with six items that load onto three factors of (1) *Personal Sacrifice Burden*, (2) *Heartfelt Sadness & Longing*, and (3) *Worry & Felt Isolation* with Cronbach's α's of .83, .80, and .80 respectively along with a total scale Cronbach's α of .90 (Marwit & Meuser, 2005). The individual factors correlated with the total short form grief scale at .85, .76, and .82 demonstrating consistency of the individual factors to the total scale (Marwit & Meuser, 2005).

Examples of items in the factor of *Personal Sacrifice and Burden* include "I've had to give up a great deal to be a caregiver" and "I wish I had an hour or two to myself each day to pursue personal interests" (Marwit & Meuser, 2005, p. 199). *Heartfelt Sadness & Longing* factor includes items such as "I have this empty, sick feeling knowing that my loved one is gone" and "I feel very sad about what this disease has done" (Marwit & Meuser, 2005, p. 199). Examples of items from the final factor of *Worry & Felt Isolation* include, "I have nobody to communicate with" and "The people closest to me do not understand what I'm going through" (Marwit & Meuser, 2005, p. 199).

The MM-CGI SF performed consistently with other measures during testing. These other measures were the same measures used in the initial development of the MM-CGI. The correlation of the total grief scale of MM-CGI SF and the Beck Depression Inventory (BDI) was .711, while the correlation with Geriatric Depression Scale Short Form (GDS SF) was .689 and the Anticipatory Grief Scale (AGS) was .760 with $p < .01$ (Marwit & Meuser, 2005). The higher correlation of the AGS was expected since both instruments are used with dementia caregivers (Marwit & Meuser, 2005). The Caregiver Strain Index (CSI) which measures potential caregiving concerns such as sleep difficulties was correlated with MM-CGI SF at .640 (Marwit & Meuser, 2005). The Caregiver Well-Being Scale-Basic Needs (WBS) and the Perceived Social Support Questionnaire-Family Sub-scale (PSSQ-FA) were inversely correlated at -.592 and -.353 (Marwit & Meuser, 2005). Therefore, the MM-CGI SF correlated well with instruments measuring depression and grief, moderately with an instrument measuring strain and inversely moderately with instruments measuring well-being and support.

Additionally, factor one, *Personal Sacrifice & Burden,* correlated high at .680 with the CSI (Marwit & Meuser, 2005). Factor one and the CSI are both examining personal loss related to the caregiving role. Factor three, *Worry and Heartfelt Isolation,* was highly inversely correlated with the PSSQ-FA at -.544 (Marwit & Meuser, 2005). Factor three examined the feeling of lack of support of the caregiver and was therefore expected to correlate inversely with the Perceived Social Support Questionnaire. Factor two examined sadness and loss concerns. Factor two correlated only modestly with the BDI and the GDS confirming that grief and depression while having some shared characteristics are different constructs (Marwit & Meuser, 2002). Validity was demonstrated in caregivers of family members diagnosed with dementia through the correlations of instruments that measure similar constructs that are a part of the grief phenomena.

MM-CGI-SF uses 5-point Likert scales ranging from 1 for *Strongly Disagree* to 5 for *Strongly Agree* (*1 = Strongly Disagree, 2 = Disagree, 3 = Somewhat Agree, 4 = Agree, & 5 = Strongly Agree*), with total scores ranging from 18 to 90. Scores can be determined by summing the points associated with the chosen Likert responses. The higher the scores, the greater the pre-death grief (Marwit & Meuser, 2002). This study used the mean score across items of the MM-CGI SF.

Dependent variable: Perceived Stress. Perceived stress for caregivers of YOD was measured using the Perceived Stress Scale 14 (PSS 14). The Perceived Stress Scale (PSS) was developed in 1983 by Cohen, Kamarck, and Mermelstein based on the Lazarus (1966) stress and coping process theory. The PSS 14 is a 14-item measure using a 5-point Likert scale (*0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, and 4 =*

very often). Respondents are asked to respond "fairly quickly" in a global sense about their feelings to statements such as "In the last month, how often have you been upset because of something that happened unexpected?" (Cohen et al., 1983, p. 394). Results are obtained by summing the scores. Seven items (numbers 4, 5, 6, 7, 9, 10, and 13) need to be reverse scored (Cohen et al., 1983). Higher PSS scores indicate higher perceived stress and subsequently an increase in health service utilization (Cohen et al., 1983).

Validity of the PSS 14 has been assessed with comparisons to the College Student Life-Event Scale, the Center for Epidemiologic Studies Depression Scale, the Cohen-Hoberman Inventory of Physical Symptoms, and The Social Avoidance and Distress Scale. Initial psychometric testing was done on two groups of college students (N = 446) and a smoking cessation group (N = 64) (Cohen et al., 1983). A moderate correlation was found to exist between scores on PSS 14 and number of life events scales. The impact scores of the life event measures "reflects the same stressor appraisal measured by the PSS 14" and had a moderate to high correlation across all samples (Cohen et al., 1983, p 390). Across all three original sample groups, PSS 14 correlated higher than the life event scales to symptom measures (.52 to .76) and to increased use of health services (Cohen et al., 1983). Validity of the PSS 14 is reflected in the moderate to high correlational scores with these instruments that appraise the impact of stressful events. The PSS 14 was a better predictor of symptoms experienced and health service utilization within four weeks of completion of the scale as compared with the other measures.

The scale inter-item correlation of the PSS 14 as measured by the Cronbach's α among the original three sample groups ranged from .84 to .86 (Cohen et al, 1983). This demonstrates good scale inter-item correlation that the items are measuring the same

factor. The original three samples had a test-retest reliability after a 2-day interval of .85 (Cohen et al, 1983). Lee (2012) found 11 studies that reported the psychometric properties, Cronbach's α, test-retest reliability, factorial validity, criterion validity, hypothesis testing and known-groups validity, of the PSS 14 in their review of the literature (Lee, 2012). The Cronbach's α of the PSS 14 ranged from .75 to .89 (Lee, 2012). The test-retest was not completed in all the articles in the review. For the PPS 14, the test-retest *r* ranged from .85 in a two-day interval and .55 in a six-week interval. This demonstrates that the stability of the PSS 14 is less than six weeks (Lee, 2012). Lee (2012) concluded in the literature review of the Perceived Stress Scale and its variations are easy to use questionnaires with acceptable psychometric properties.

Moderating variable: Resourcefulness. Resourcefulness was measured using the Resourcefulness Scale (RS). Zauszniewski developed the RS with two different subscales to assess both personal resourcefulness and social resourcefulness (Zauszniewski et al., 2006). The 28 item RS scores range from 0-140 with higher scores indicating greater resourcefulness Cronbach's α for the full scale was .85 with the 12 items for the social resourcefulness subscale equal to .79 and 16 items for the personal resourcefulness subscale equal to .83. Evaluation of the item-to-total and the inter-item correlations demonstrated the scale would not be improved with the deletion of any of the current items (Zauszniewski et al., 2006).

Personal resourcefulness is the ability problem solve, effectively cope, and manage all daily activities (Zauszniewski et al., 2006). This ability is considered self-control behaviors. These behaviors were previously measured on the Self-Control Scale created by Rosenbaum (1980). The personal resourcefulness subscale consists of 16

items on a 6-point Likert scale (*0 = not at all like me, 1 = pretty much not like me, 2 = a little bit not like me, 3 = a little bit like me, 4 – pretty much like me and 5 = very much like me*). Scores range from 0 to 80 with higher scores indicative of greater personal resourcefulness skills. Examples of personal resourcefulness items include "When I am faced with a number of things to do, I usually plan my work" and "When I am feeling depressed, I try to think about pleasant events" (Zauszniewski et al., 2006).

Social resourcefulness is the ability to seek out and access services and resources when assistance is needed (Zauszniewski et al., 2006). This ability is considered help seeking behavior and was earlier measured using the Help-Seeking Resource Scale developed by Zauszniewski in 1998. Behaviors that are considered help-seeking or social resourcefulness are seeking help from a friend when needed (Zauszniewski et al., 2006). The social resourcefulness subscale has 12 items using a 6-point Likert scale (0 = not at all like me, 1 = pretty much not like me, 2 = a little bit not like me, 3 = a little bit like me, 4 – pretty much like me and 5 = very much like me). Scores range from 0 to 60 with higher scores indicative of greater social resourcefulness skills. Examples of social resourcefulness items are "When I am feeling sad, it helps to talk to other people" and "When it is hard for me to make a decision, I ask someone to help me think things through" (Zauszniewski et al., 2006).

The RS found personal resourcefulness and social resourcefulness are complimentary elements that are equally important in the concept of resourcefulness with substantial inter-correlation between the subscales ($r = .41$, $p < .001$) (Zauszniewski et al., 2006). The RS has been used in studies with dementia caregivers resulting in Cronbach's

α of .92 (Bekhet, 2013), .81 (Zauszniewski et al., 2015) and .79 (Zauszniewski et al., 2016).

Appendix A contains a copy of the instruments utilized in this study along with permission letters to utilize the instruments that were not in the public domain and instrument scoring instruction.

Table 3.1

Summary of instruments

Variables	Concepts	Measurements	Number of items	Score range	Total scores	Reliability reported
Independent	Pre-death Grief	Marwit Meuser Caregiver Grief Inventory – Short Form (MM-CGI SF)*	18 items	1-5	18-90	.75
Dependent	Perceived Stress	Perceived Stress Scale 14 (PSS 14)*	14 items	0-4	0- 56	.78
Moderating	Resourceful-ness	Resourcefulness Scale (RS)*	28 items	0-5	0-140	.85
Subscale		Social Resourcefulness	12 items	0-5	0-60	.79
Subscale		Personal Resourcefulness	16 items	0-5	0-80	.83

* (Cohen, 1988; Meuser & Marwit, 2005; Zauszniewski et al., 2006; respectively).

Protection of Human Subjects

In alignment with United States Health and Human Services code of federal regulations, approval for this study was obtained from Marquette University (MU) through the MU Institutional Review Board (IRB) for the protection of participants in the study. Informed consent was obtained from all participants prior to data collection. Participants accessed the study through a computer link. The initial page delineated the purpose of the study, procedure, participant's rights during the study, participation risks and benefits, and contact information for the lead researcher. Participants were informed of the voluntary nature of their participation with the right to refuse and withdraw without any consequences at any time. Survey completion was anonymous. Survey information was downloaded from online survey platform into a spreadsheet that is coded so that anonymity was maintained. Participants continuing forward to the survey implied agreement to participate and acceptance of informed consent. It was estimated that the participants were able to complete the online surveys in under 20 minutes.

Study results are presented in an aggregate format. Indirect benefits can be obtained from this study. The information provided by caregivers benefits others by assisting health professionals in identifying more effective ways for helping caregivers to cope with the stress of caregiving. No hazardous procedures were involved. There was no physical risk to participants. Similar surveys that have been used with caregivers did not show that such surveys were stressful for them. Interested participants can contact the researcher via email if there were questions regarding the survey.

Data Collection

Data were collected until an adequate sample is obtained. Between September 2017 and the beginning of April 2018, 104 surveys were collected. Informed consent was obtained through the first screen of the computer survey. This screen gave information regarding the survey, purpose of the survey, voluntary nature of survey, rights of the participants including anonymity and confidentiality, right to terminate participation of survey at any time, and information on result dissemination as aggregate data. The researcher provided an email address if participants have any questions. Participants agreed to take the survey if they click "next screen" button which began the survey. If participants clicked "no" on either screen, the survey ended with participants being thanked for their participation.

The initial survey screen was the MM-CGI SF. This screen was followed by screens for the PSS 14 and then the RS. The final screen was demographic information which included gender, age, race/ethnicity, educational level, socioeconomic status and health appraisal questions. Each question needed to be answered prior to moving on to the next question. At the completion of the measures and demographics, participants were thanked for their participation and linked to a $20.00 gift card. Estimated time to complete survey was twenty minutes.

Appendix B contains institutional review board forms, informed consent and demographic information for the study survey.

Data Management

Data records were downloaded and kept in a password protected file. Surveys were completed anonymously. There was no way to link data back to any individual participant. Data was uploaded directly from online survey platform to R (R Core Team, 2017) for analysis.

Data Analysis

Data analysis was performed using R (R Core Team, 2018) with the packages lavaan (Rosseel, 2012) and semTools (SemTools Contributors, 2018). The reliability was evaluated with the maximal reliability coefficient (*MR*). This coefficient estimates the reliability of a scale assuming items have different weights. The *MR* is the maximal possible reliability for a linear combination of the scale items. This involves the estimation of the optimal linear combination. *MR* measures reliability of a scale, unlike Cronbach α which estimates inter-item correlation (Raykov, 2012). *MR* is estimated with the R package semTools.

Descriptive statistics were used to describe the sample. Data analysis occurred using R to evaluating bivariate correlations using Pearson's correlation coefficient (*r)* and the coefficient of determination (R^2).

The association between pre-death grief and perceived stress was evaluated with linear models, establishing the relation as correlation and regression. The initial relation between pre-death grief and perceived stress is set as a linear correlation to answer hypothesis 1. After that, to answer hypotheses 2a and 2b, regression models were used to

evaluate pre-death grief, personal resourcefulness, and social resourcefulness as predictors of perceived stress. To evaluate the moderating effect of personal resourcefulness and social resourcefulness on the regression of pre-death grief on perceived stress, interactions between pre-death grief and the resourcefulness scores were calculated (Pre-death Grief *Personal Resourcefulness, and Pre-death Grief *Social Resourcefulness) and added as predictors of perceived stress. The relevance of the interactions was tested by the *p*-value of the interaction regressions and the change in R^2 when the interactions are included, and finally by plotting and probing the interaction effects (Darlington, & Hayes, 2017).

Plotting and probing the interaction estimates the intercept and slope for the regression of interest (pre-death grief → perceived stress) conditional on the moderating variables, in this case personal resourcefulness, and social resourcefulness. This means that the intercept and slope were estimated at different values of personal resourcefulness and social resourcefulness, allowing for the evaluation of how personal resourcefulness and social resourcefulness change the regression. With probing, the null hypothesis was tested for the regression at each conditional value, while with plotting these regressions were visualized (Darlington, & Hayes, 2017).

These regressions were evaluated in the framework of Structural Equation Modeling with path analysis (Kline, 2016). Missing data were handled with Full Information Maximum Likelihood, which is a proper method to handle missing data while reducing bias since subjects are not excluded from the analysis (Enders, 2010).

H1: Caregiver pre-death grief has a positive association with caregiver perceived stress in caregivers of a partner with YOD.

It was predicted that as pre-death scores via the MM-CGI SF increase demonstrating an increase in pre-death grief amongst caregivers for partners with YOD, the values on the PSS 14 measuring caregiver perceived stress would increase. Data analysis occurred using R to evaluating bivariate correlations using Pearson's correlation coefficient (*r)* and the coefficient of determination (R^2). Correlational research examines relationships versus cause and effect. This was determined if there is a positive relationship between pre-death grief and perceived stress among caregivers of partners with YOD. If pre-death scores rise, it was predicted that perceived stress scores also rose. The coefficient of determination (R^2) determined the shared variability of pre-death grief and perceived stress of caregivers of partners with YOD (Field, 2013). In other words, the percentage of pre-death grief that was shared with perceived stress was determined.

H2a: Social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

H3b: Personal resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Moderator variables are a third variable that is an independent variable (Bennett, 2000). Moderation occurs when the third variable interacts with the independent variable to change the relationship between the independent variable of pre-death grief and the dependent variable of perceived stress (Bennett, 2000). Moderation was seen if scores on the RS reflect change in the relationship between pre-death grief and perceived stress. It was anticipated that high scores in resourcefulness indicated lower scores in perceived stress even with high scores of pre-death grief. The moderation was tested with multiple

regression and interpreted by simple slopes and plotting the change in relation given different values of the moderators.

Limitations

There are numerous limitations in this study. The cross-sectional design examines caregiver's pre-death grief and perceived stress at a single point in time. As caregiving for a partner with YOD can be a lengthy experience, pre-death grief and perceived stress may be influenced by events occurring at that point time. Future studies may include longitudinal studies that evaluate these variables and how they may change over time. Correlational studies lack the ability to demonstrate causal relationships amongst the variables (Polit & Beck, 2017).

A convenience sample may not adequately represent the population of study (Polit & Beck, 2017). Convenience samples are open to selection bias and availability of potential participants. Therefore, results cannot be generalized to all caregivers of partners with YOD.

Summary

This cross-sectional, correlational study used a convenience sample to examine/explore the relationship between pre-death grief and perceived stress of caregivers of partners with YOD. Additionally, this study examined personal and social resourcefulness as a moderator of this relationship using multiple regression. Results add to nursing knowledge regarding factors that influence caregiver perceived stress. This

guides future interventions that may support caregivers of partners with YOD and enhance their overall well-being.

CHAPTER IV
Manuscript I: Concept Analysis

Manuscript I is a concept analysis of resilience as found in caregivers of partners diagnosed with YOD and is referenced:

Kobiske, K. & Bekhet, A. (2018). Resilience in caregiver of partners with young onset dementia: A concept analysis. *Issues in Mental Health Nursing, 39*(5), p 411-419. doi: 10.1080/01612840.2017.1400625.

CHAPTER V

Manuscript II: Results & Interpretation of Findings

The interpretation of findings for this study are found in Manuscript II in Appendix C and are not duplicated in this section. The manuscript is titled: “Pre-death grief, resourcefulness and perceived stress among partners of young onset dementia” and will be submitted to the *Western Journal of Nursing Research* in June 2018.

REFERENCES

Allen, A.P., Curran, E.A., Duggan, A., Cryan, J.F., Chorcorain, A.N., Dinan, T.G., Molloy, D.W., Kearney, P.M. & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive biological markers of stress. *Neuroscience and Biobehavioral Reviews, 73,* 123-164. doi: 10.1016/j.neubiorev.2016.12.006.

Alzheimer's Association. (2018). *2018 Alzheimer's disease facts and figures.* www.alz.org.

Alzheimer's Association. (2006). *Early onset dementia: A national challenge; a future crisis*. www.alz.org.

Alzheimer's Association & National Alliance for Caregiving (2004). *Families care: Alzheimer's caregiving in the United States.* www.alz.org/national/documents/caregiver.pdf.

American Psychological Association. (2014). *The road to resilience.* Washington, DC: American Psychological Association. Retrieved from http://www.apa.org/helpcenter/road-resilience.aspx.

Aria, A., Matsumoto, T., & Aria, Y. (2007). Do family carers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry,* 22(12), 1255-1261. doi: 10.1002/gps.1935.

Armani, E., Jarmolowicz, A. & Panegyres, P. (2012). The needs of patients with early onset dementia. *The American Journal of Alzheimer's Disease and other Dementias,* 28(1), 42-46. doi: 10.1177/1533317512466690.

Bekhet, A.K., (2013). Effects of positive cognitions and resourcefulness on caregiver burden among caregivers of persons with dementia. *International Journal of Mental Health Nursing 2,* 340-346. doi: 10.1111/j.1447-0349.2012.00877.x.

Bekhet, A.K. (2015). Resourcefulness in African American and Caucasian American caregivers of persons with dementia: Associations with perceived burden, depression, anxiety, positive cognitions, and psychological well-being. *Perspectives in Psychiatric Care, 51,*285-294. doi: 10.1111/ppc.12095.

Bekhet, A.K. & Zauszniewski, J. (2008). Theoretical substruction illustrated by the theory of learned resourcefulness. *Research and Theory for Nursing Practice, 22*(3), 205-214. doi: 10.1891/1541-6577.22.3.205.

Bennett, J.A. (2000). Mediator and moderator variables in nursing research: Conceptual

and statistical differences. *Research in Nursing & Health, 23*, 415-420. doi: 10.1002/1098-240x(200010)23:5<415:AID-NUR>3.0.COj2-H.

Betts Adams, K. & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: A mixed-method analysis. *Dementia,* 3(2), 195-210. doi: 10.1177/1471301204042337.

Blandin, K. & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia, 0*(0), 1-12. doi: 10.1177/1471301215581081.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge, MA: Harvard University Press.

Cabanyes Truffino, J. (2010). Resilience: An approach to the concept. *Revista de Psiquiartia y Salud Mental. 3*(4), 145-151. doi: 10.1016/S2173-5050(10)70024-8.

Cabote, C.J., Bramble, M., & McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing,* 1-26. doi: 10.177/1074840715573870.

Cannon, W.B. (1932). *Wisdom of the body.* New York: W.W. Norton and Company.

Chan, S.W. (2010). Family caregiving in dementia: The Asian perspective of a global problem. *Dementia and Geriatric Cognitive Disorder, 30*, 469-478. doi: 10.1159/000322086.

Cherry, M.G., Salmon, P., Dickson, J.M., Powell, D., & Sikdar, S. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology, 23*(4), 251-266. doi: 10.1017/S0959259813000130.

Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a partners. *New England Journal of Medicine. 354*, 719-730. doi: 10.1056/NEJMsa050196.

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159. doi: 10.1037/0033-2909.112.1.15.

Cohen's *Laboratory for Stress, Immunity, and Disease* (2012). http://www.psy.cmu.edu~scohen.

Cohen, S., Janicki-Deverts, D., & Miller G.E. (2007). Psychological stress and disease. *Journal of the American Medical Association, 298,* 1684-1687. doi: 10.1001/jama.298.14.1685.

Cohen, S., Kamarck, T. & Mermelstein R. (1983). A global measure of perceived

stress. *Journal of Health and Social Behavior, 24*(4), 385-396. url: http://www.jstor.org/stable/2136404.

Cohen's S. & Williamson, G. (1988). Perceived stress in a probability sample in the United States. In Spacapan, & Oskamp (Eds.), *The social psychology of health: Claremont symposium on applied social psychology.* Newbury Park, CA: Sage.

Darlington, R. B., & Hayes, A. F. (2017). *Regression Analysis and Linear Models. Concepts, Applications, and Implementation*. New York, NY, US: The Guilford Press.

Deist, M., & Greeff, A.P. (2015). Resilience in families caring for a family member diagnosed with dementia. *Educational Gerontology, 41*(2), 93-105. doi: 10.1080/03601277.2014.942146.

Donaldson, R.J. & Donaldson, L.J. (1998) *Essential public health medicine.* London, UK. Libra Pharm Ltd.

Drummond, S., O'Driscoll, M.P., Brough, P., Kalliath, T., Sui, O., Timms, C. & Riley, D. (2017). The relationship of social support with well-being outcomes via work-family conflict: Monitoring effects of gender, dependents, and nationality. *Human Relations, 70*(5), 544-565.doi: 10.1177/0018726716662696.

Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F. & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *The American Journal of Alzheimer's Disease and other Dementias,* 28(6), 634-641, doi: 10.1177/1533317513494443.

Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F., & Coulombe, R. (2014). Caring for individuals with early-onset dementia and their family caregivers: The perspective of health care professionals. *Advances in Alzheimer's Disease,* 3, 33-43, doi: 10.4236/aad.2014.31005.

Earvolino-Ramirez, M., (2007). Resilience: A concept analysis. *Nursing Forum, 42*(2), 73-82. doi: 10.1111/j.1744-6198.2007. x.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175-191. doi: 10.3758/BF0319346.

Fawcett, J. (1999). *The relationship of theory and research (3rd ed).* Philadelphia: F.A. Davis.

Field, A. (2013). *Discovering Statistics using IBM SPSS Statistics 4th edition*. Los Angeles: Sage Publishing.

Fischer, G. G., Franks, M. M., Plassman, B. L., Brown, S. L., Potter, G. G., & Llewellyn, D. (2011). Caring for individuals with dementia and cognitive impairment, not dementia. *Journal of American Gerontology Society.* 59(3), 488-494. doi: 10.111/j.1532-5414.2010.03304x.

Fletcher, D., & Sarkar, M. (2013). Psychological resilience: A review and critique of definitions, concepts, and theory. *European Psychologist*, *18*(1), 12-23. doi: 10.1027/1016-9040/a000124.

Flynn, R. & Mulcahy, H. (2013). Early onset dementia: The impact on family care-givers. *British Journal of Community Nursing,* 18(12), 598-606. doi: 10.1177/1471301216661427.

Fonareva, I. & Oken, B. (2015). Physiological and functional consequences of caregiving for relatives with dementia. *International Journal of Psychogeriatric, 26*(5), 725-747. doi: 10.1017/S1041610214000039.

Frank, J.B. (2007). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias. 22*(6), 516-527. doi: 10.1177/1533317507307787.

Garcia-Dia, M.J., DiNapoli, J.M., Garcia-Ona, L., Jakubowski, R., & O'Flaherty, D. (2013). Concept analysis: Resilience. *Archives of Psychiatric Nursing, 27,* 264-270. doi: 10.1016/j.apnu.2013.07.003.

Geanelios, R. (1992). Nursing knowledge development: Where to from here? *Royal College of Nursing, Australia, 4*(1), 13-21. PMID: 9272005.

Gibson, A.K., Andersen, K.A., & Acocks, S. (2014). Exploring the service and support needs of families with early-onset Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 29*(7), 596-600. doi: 10.1177/1533317514558160.

Gillespie, B., Chaboyer, W., & Wallis, M. (2007). Development of a theoretically derived model of resilience through concept analysis. *Contemporary Nurse*, *25,* 124-135. doi: 10.5555/conu.2007.25.1-2.124.

Gray, D.E. (2013). *Doing research in the real world (3rd ed.).* Los Angeles: Sage.

Guba, E.G. (1990). *The paradigm dialog.* Newbury Park: Sage.

Herrman, H., Stewart, D., Diaz-Granados, N., Berger E., Jackson, B., & Yuen, T. (2011) What is resilience. *The Canadian Journal of Psychiatry. 56*(5), 258-265. doi: 10.1177/070674371105600504.

Holley, C.K., & Mast, B.T. (2009). The impact of anticipatory grief on caregiver burden

In dementia caregivers. *Gerontologist, 49*(3), 388-396. doi: 10.1093/geront/gnp061.

Jacobs, S.R., (1993). An analysis of the concept of grief. *Journal of Advanced Nursing*. 18, 1787-1794. PMID: 828825.

Kaiser, S. & Panegyres, P. (2007). The psychosocial impact of young onset dementia on partners. *The American Journal of Alzheimer's Disease and other Dementias,* 21(6), 398-402, doi: 10.1177/1533317506293259.

Kiefer, R.A. (2008). An integrative review of the concept of well-being. *Holistic Nursing Practice, 22*(5), 244-252. doi: 10.1097/01.HNP.0000334915.16186.b2.

Kline, R. B. (2016). *Principles and practice of structural equation modeling* (Fourth Edition). New York: Guilford Press.

Lazarus, R. (1966). *Psychological Stress and the Coping Process.* New York: McGraw-Hill.

Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* New York: Springer.

Lee, E.H. (2012). Review of the psychometric evidence of the perceived stress scale. *Asian Nursing Research, 6*, 121-127. doi: 10.1016/j.anr.2012.08.004.

Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70(10), 2196-2207. doi:10.1111/jan.12411.

Llanque, S., Savage, L., Rosenburg, N., & Caserta, M. (2016). Concept analysis: Alzheimer's caregiver stress. *Nursing Forum, 51*(1), 21-31. doi: 10.1111/nuf.12090.

Lockeridge, S., & Simpson, J. (2012). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia,*12 (5), 635-651, doi: 10.1177/1471301212440873.

Luther, S. S., & Cicchetti D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychology, 12*, 857-885. doi: 10.1017/S0954579400004156.

Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42(6), 751-765. PMID: 12451156.

Marwit, S.J. & Meuser, T.M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies, 29,* 191-205. doi:

10.1080/07481180590916335.

Melnyk, B.M. & Fineout-Overhot E. (2011). *Evidence-based practice in nursing and healthcare: A guide to best practice*. Philadelphia: Lippincott, Williams & Wilkins.

MetLife Mature Market Institute. (2006). *The MetLife study of Alzheimer's disease: The caregiving experience.* www.maturemarketinstitute.com.

Meuser, T.M. & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41,* 658-700. PMID: 11574711.

Meuser, T., Marwit, S. & Sanders, S. (2004). Assessing grief in family caregivers. In: Doka KJ (eds). *Living with Grief: Alzheimer's disease.* Washington DC: Hospice Foundation of America, 169-198. doi: 10.1177/533317509333902.

Millenaar, J.K., Bakker, C., Koopsman, R.T.C.M., Verhey, F.R.J., Kurz, A., & de Vugt, M.E. (2016). The care needs and experiences with the use of services of people With young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry, 31,* 1261-1276. doi: 10.1002/gps.4502.

National Alliance for Caregiving and AARP. (2009). *Caregiving in the US.* Unpublished data analyzed under contract for the Alzheimer's Association.

Noyes, B.B., Hill, R.D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N.K., Bair, B. D. (2009). Review: The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias,* 25(1), 9-17. doi: 10.1177/1533317509333902.

O'Rourke, N., Kupferschmidt, A., Claxton, A., Smith, J., Chappell, N., & Beattie, B. (2010). Psychological resilience predicts depressive symptoms among spouse of persons with Alzheimer's disease overtime. *Aging and Mental Health, 14*(8), 984-993. doi: 10.1080/13607863.2010.501063.

Ott, C.H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *The Gerontologist,* 47(6), 798-809. doi: 10.1093/geront/47.6.798.

Paun, O., Farran, C.J., Fogg, L., Loukissa, D., Thomas, P.E., & Hoyem, R. (2015). A chronic grief intervention for dementia family caregivers in long-term care. *Western* Journal *of Nursing Research,* 37(1), 6-27. doi: 10.1177/0193945914521040.

Persson, J. (2009). Misconceptions of positivism and five unnecessary science theoretic

mistakes they bring in their train. *International Journal of Nurisng Studies, 47,* 651-661. doi: 10.1016/j.ijnurstu.2009.12.09.

Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBI Database of Systematic Reviews and Implementation Reports* doi: 10.11124/JBISRIR-2016-002555.

Pfau, M.L. & Russo, S.J. (2015). Peripheral and central mechanisms of stress resilience. *Neurobiology of Stress, 1,* 66-79. doi: 10.1016/j.ynstr.2014.09.004.

Polit, D.F., & Beck, C.T. (2017). *Nursing research: Generating and assessing evidence for nursing practice (10th ed.).* Philadelphia: Wolters Kluwer.

R Core Team (2018). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL https://www.R-project.org/

Raykov, T. (2012). Scale construction and development using structural equation modeling. In R. H. Hoyle (Ed.), *Handbook of structural equation modeling* (pp. 472-494). New York: Guilford.

Read, S. (2005). Loss, bereavement and learning disabilities: Providing a continuum of support. *Learning Disability Practice, 8*(1), 31- 37. doi: 10.7748/ldp2005.02.8.1.31.c1605.

Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W., & Greenwood, N. (2016). Psychosocial interventions for people with young onset dementia and their carers: A systematic review. *International Psychogeriatrics, 28*(9), 1441-1454. doi: 10.1017/S1041610216000132.

Richardson, G.E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology, 58,* 307-321. doi: 10.1002/jclp.10020.

Roach P., Keady, J., Bee, P., & Hope, K. (2009). Subjective experiences of younger people with dementia and their families: Implications for UK research, policy and practice. *Clinical Gerontology,* 18, 165-174, doi: 10.1017/S0959259809002779.

Romero, M. M., Ott, C.H., & Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. *Death Studies,* 38(6), 395-403. doi: 10.1080/07481187.2013.809031.

Rosenbaum, M. (1980). A schedule for assessing self-control behaviors: Preliminary findings. *Behavioral Therapy, 11,* 109-121. doi: 10.1177/1073191104268199.

Rosenbaum, M. (1983). Learned resourcefulness as a behavioral repertoire for the

Self-regulation of internal events: Issues and speculations. In M. Rosenbaum, C. M. Franks, & Y. Jaffe (Eds.), *Perspectives on behavior therapy in the eighties* (pp. 54-73). New York: Springer.

Rosenbaum, M. (1990). *Learned resourcefulness on coping skills, self-control, and adaptive behavior.* New York: Springer Publishing.

Rosenthal Gelman, C., & Greer, C. (2011). Young children in early-onset Alzheimer's disease families: Research gaps and emerging service needs. *The American Journal of Alzheimer's Disease and other Dementias,* 26(1), 29-35, doi: 10.1177/1533317510391241.

Rosness, T.A., Haugen, P.T., Gausdalh, M., Sjora, L., & Engedal, K. (2012). Carers of patients with early onset dementia, their burdens and needs: A pilot study using a new questionnaire – care – eod. *International Journal of Geriatric Psychiatry, 10*, 1095-1096. doi: 10.102/gps.2818.

Rosness, T.A., Mjorud, M., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onset dementia. *Aging and Mental Health, 15*(3), 299-306. doi: 10.1080/13607861003713224.

Rosseel, Y (2012). lavaan: An R Package for Structural Equation Modeling. Journal of Statistical Software, 48(2), 1-36. URL http://www.jstatsoft.org/v48/i02/'

Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry, 147*, 598-611. doi: 10.1192/bjp.147.6.598.

Rutter, M. (2012). Resilience as a dynamic concept. *Development and Psychopathology, 24*, 335-344. doi: 10.1017/S0954579412000028.

semTools Contributors. (2018). semTools: Useful tools for structural equation modeling. R package version 0.4-15.918. Retrieved from https://CRAN.R-project.org/package=semTools

Shuter, P., Beattie, E., & Edwards, H. (2013). An exploratory study of grief and health related quality of life for caregivers of people with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 29*(4), 379-385. doi: 10.1177/153331751357034.

Smith-Osbourne, A. & Felderhoff, B. (2014). Veterans informal caregivers in the "sandwich generation": A review toward resilience model. *Journal of Geriatric Social Work, 57*(6-7), 556-584. doi: 10.1080/016314372.2014.880101.

Southwick, S.M., Bonanno, G.A., Masten, A.S., Panter-Brick, C. & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives.

European Journal of Psychotraumatology, 5, 1-14. doi: 10.3402/ejpt.v5.25338.

Spreadbury, J.H., & Kipps, C. (2017). Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia, 0*(0), 1-20. doi: 10.1177/1471301216684401.

Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregiver of persons with dementia. *Dementia, 13*(6), 803-818. doi: 10.1177/1471301213485593.

Svanberg, E., Spector, A. & Stott, J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatric,* 23(3), 356-371, doi: 10.1017/S1041610210001353.

Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging and Mental Health,* 14(6), 741-750, doi: 10.1080/1360786100371374.

Teles Vieira, R., Caixeta, L., Machado, S., Silva, A.C., Nardi, E., Arias-Carrion, O., & Carta, M.G. (2013). Epidemiology of early onset dementia: A review of the literature. *Clinical Practice & Epidemiology in Mental Health, 9,* 88-95. doi: 1745-0179/13.

van Vliet, D., de Vugt, M., Bakker, C., Koopmans, R., & Verhey, F., (2010). Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry,* 25, 1091-1100, doi: 10.1002/gps.2439.

Videbeck, S.L. (2010). *Psychiatric-mental health nursing,* (5th ed.). Philadelphia: Lippincott Williams & Wilkins.

von Kanel, R., Dimsdale, J. E., Mills, P. J., Ancoli-Isreal, S., Patterson, T. L., & Mausback, B. T. (2006). Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. *Journal of Gerontology: Medical Science.* 61A (9):963-9. doi: 10.1.1543.6262&rep=rep1.

Wachol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., & Madeda, A. (2014). What causes grief in dementia caregivers? *Achieves of Gerontology and Geriatrics, 59,* 462-467. doi: 10.1016/j.achger.2014.05.013.

Wald, J., Taylor, S., & Asmundson, G. (2006). *Literature review of concepts: Psychological resiliency*. Toronto, ON: Defense R & D Canada.

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M., & Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics.* doi: 10.1111/psyg.12234.

Werner, P., Stein-Shvachman, I., & Korczyn, A. (2009). Early onset dementia: Clinical and social aspects. *International Psychogeriatrics. 21*(4), 631-636, doi: 10.1017/S104161020900923.

Wilks, S.E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging and Mental Health, 12*(3), 357-365. doi: 10.1080/13607860801933323.

Windle, G. (2011). What is resilience? A review and concept analysis. *Clinical Gerontology, 21,* 152-169. doi: 10.1017/S0959259810000420.p

Wisconsin Department of Health Services. (2014). *Wisconsin Dementia Care System Redesign: Plan for a dementia capable Wisconsin.*

Zauszniewski, J.A., Bekhet, A.K., & Suresky, M.J. (2009). Effects on resilience of women family caregivers of seriously mentally ill adults: The role of positive cognitions. *Archives of Psychiatric Nursing, 23*(6), 412-422. doi: 10.1016/j.apnu.2008.12.004.

Zauszniewski, J.A., Bekhet, A.K., & Suresky, M.J. (2010). Resilience in family members of persons with serious mental illness. *Nursing Clinics of North America, 45,*613-626. doi: 10.1016/j.cnur.2010.06.007.

Zauszniewski, J.A., Lau, C.Y., & Tithiphontumrong, S. (2006). Development and testing of a resourcefulness scale for older adults. *Journal of Nursing Measurement, 14*(1), 57-68. PMID: 16764178.

Zauszniewski, J.A., Lekhak, N., Napoleon, B., & Morris, D.L. (2016). Resourcefulness training for women dementia caregivers: Acceptability and feasibility of two methods. *Issues in Mental Health Nursing, 37*(4), 249-256. doi: 10.3109/01612840.2015.1119222.

Zauszniewski, J.A., Lekhak, N., Yolpant, W., & Morris, D.L. (2015). Need for resourcefulness training for women caregivers of elders with dementia. *Issues in Mental Health Nursing, 36*(12), 1007-1012. doi: 10.3109/01612840.2015.1075236.

Zauszniewski, J.A.; McDonald, P.E., Krafick, K. & Chung, C. (2002). Acceptance, cognitions, and resourcefulness in woman with diabetes. *Western Journal of Nursing Research, 24*(7), 728-743. doi: 10.1177/019394502762476951.

APPENDIX A

Appendix A contains the instruments utilized in this study and a copy of permission letters when required. Instruments included are the MM-CGI SF, PSS 14 and RS.

MM-CGI SF

MM Caregiver Grief Inventory - Short Form

Thomas M. Meuser, Ph.D., University of Missouri – St. Louis
Samuel J. Marwit, Ph.D., University of Missouri-St. Louis (Emeritus)

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed below.

ANSWER KEY
1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // **5 = Strongly Agree**

1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I feel I am losing my freedom.	1	2	3	4	5	A
3	I have nobody to communicate with.	1	2	3	4	5	C
4	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5	B
5	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
6	Dementia is like a double loss…I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5	C
7	My friends simply don't understand what I'm going through.	1	2	3	4	5	C
8	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
9	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
10	I will be tied up with this for who knows how long.	1	2	3	4	5	A
11	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5	B
12	I feel very sad about what this disease has done.	1	2	3	4	5	B
13	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
14	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
15	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
16	Independence is what I've lost…I don't have the freedom to go and do what I want.	1	2	3	4	5	A
17	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
18	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.

Personal Sacrifice Burden *(A Items)* = _____
(6 Items, M = 20.2, SD = 5.3, Alpha = .83, n = 292)

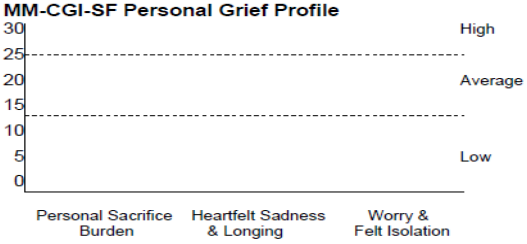
Heartfelt Sadness & Longing *(B Items)* = _____
(6 Items, M = 20.2, SD = 5.0, Alpha = .80, n = 292)

Worry & Felt Isolation *(C Items)* = _____
(6 Items, M = 16.6, SD = 5.2, Alpha = .80, n = 292)

Total Grief Level (Sum A + B + C) =_____
(18 Items, M = 57, SD = 12.9, Alpha = .90, n = 292)

Plot your scores using the grid to the right. Make an "**X**" nearest to your numeric score for each sub-scale heading. Connect the X's. This is your grief profile. Discuss this with your support group leader or counselor.

MM-CGI-SF Personal Grief Profile



What do these scores mean?
Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 292). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only— more research is needed on specific interpretation issues.

RE: MM-CGI SF

Meuser, Thomas <meusert@umsl.edu>

Reply all

Wed 6/7/2017, 1:47 PM

Ruekert Kobiske, Karie;

Bekhet, Abir;

Frenn, Marilyn

Inbox

You replied on 6/7/2017 2:11 PM.

Marwit & Meuser 2002 - compressed.pdf 551 KB	Marwit & Meuser 2005.pdf 263 KB	Meuser & Marwit 2001 Gerontologist.pdf 100 KB	MM-CGI Short Form.pdf 17 KB	MM-CGI-50 Full Version.pdf 29 KB

Karie:

Thanks for your note and interest in using the MMCGI Short Form. I ask that folks contact me so I can ensure that the scale is being used properly. Your study sounds very worthwhile, and you have my support.

I have two requests:

1. That you reference all three papers that, together, show the development of the scale. I have attached these for your information and use.
2. Should you wish to alter any items, I ask that you contact me first. I had a bad experience with this scale years ago. A physician researcher changed items and even renamed the scale and then published it. He did not have my permission to do this. You can understand why I would want to avoid that.

While I am not doing research in this area any longer, I remain very interested. Feel free to contact me if I can help along the way. Best wishes for your study.

Tom Meuser

_____

Tom Meuser, PhD
Professor of Gerontology & Clinical Psychologist
Director, Gerontology Program
Coordinator, UMSL Life Review Project
Department of Sociology, Gerontology & Gender
University of Missouri – St. Louis
574A Clark Hall, 1 University Blvd.
St. Louis, MO 63121
Office: 314-516-5421
Cell: 314-402-8638
Faculty Page: http://www.umsl.edu/gerontology/Faculty%20and%20Staff/meuser.html

PSS-14

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, you will be asked to indicate your response by placing an "X" over the circle representing HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

Item	Question	Never	Almost Never	Some times	Fairly Often	Very Often
1	In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2	In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3	In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4	In the last month, how often have you dealt successfully with day to day problems and annoyances?	4	3	2	1	0
5	In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	4	3	2	1	0
6	In the last month, how often have you felt confident about your ability to handle your personal problems?	4	3	2	1	0
7	In the last month, how often have you felt that things were going your way?	4	3	2	1	0
8	In the last month, how often have you found that you could	0	1	2	3	4

	not cope with all the things that you had to do?					
9	In the last month, how often have you been able to control irritations in your life?	**4**	**3**	**2**	**1**	**0**
10	In the last month, how often have you felt that you were on top of things?	**4**	**3**	**2**	**1**	**0**
11	In the last month, how often have you been angered because of things that happened that were outside of your control?	**0**	**1**	**2**	**3**	**4**
12	In the last month, how often have you found yourself thinking about things that you have to accomplish?	**0**	**1**	**2**	**3**	**4**
13	In the last month, how often have you been able to control the way you spend your time?	**4**	**3**	**2**	**1**	**0**
14	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	**0**	**1**	**2**	**3**	**4**

RS

The RS is not in public domain. Permission with a copy of the instrument and scoring was obtained from Dr. Zauszniewski. Below is a copy of the permission letter.

April 19, 2017

Karie Ruekert Kobiske
PhD Nursing Student
Marquette University
Milwaukee, WI

Dear Ms. Kubiske,

Thank you for your interest in using the Resourcefulness Scale (RS) for your dissertation research on caregivers of persons with young onset dementia in which you plan to examine the relationship between anticipatory grieving and caregiver well-being and the potential mediating or moderating effects of resourcefulness on that relationship. As the developer and owner of this scale, I give you my permission to use it in your dissertation study.

With this letter, I am providing to you a copy of the instrument, scoring guide, and references for publications describing the theory on which it is based and its reliability and validity. I ask that you not alter the items, scaling, or scoring of the RS without notification and request for further permission as needed.

I am available to provide consultation to you in regard to the use of the scale, interpretation of its scoring, and analysis of aggregated data obtained from your study participants. And, I would ask that following your study, you would provide for me a summary of the findings in relation to the psychometric properties of the RS measure in your study population. I wish you success on your dissertation and completion of your PhD degree.

Best regards,

Jaclene A. Zauszniewski

Jaclene A. Zauszniewski, PhD, RN-BC, FAAN
Kate Hanna Harvey Professor in Community Health Nursing
Bolton School of Nursing, Case Western Reserve University

APPENDIX B

Appendix B contains the IRB approval form, Informed Consent screen, and demographics screen.

IRB Approval

Office of Research Compliance

Schroeder Complex, 102
P.O. Box 1881
Milwaukee, Wisconsin 53201-1881

P 414.288.7570
F 414.288.6281
W marquette.edu/researchcompliance

Date: 09/06/2017
HR-3385
Principal Investigator: Dr. Karie Ruekert Kobiske
Faculty Advisor: n/a
Department: Nursing
Study Title: Pre-death grief, resourcefulness, and perceived stress among caregivers of partners with young onset dementia

New Study Approval	
☒	This protocol has been determined to be Exempt under category **2** as governed by 45 CFR 46.101(b).
☐	This protocol has been approved as minimal risk under Expedited category # as governed by 45 CFR 46.110.
☐	This protocol has been reviewed by the Institutional Review Board on [date] and approved as:
	☐ Minimal risk
	☐ Greater than minimal risk

Approval Date	
☒	This exempt determination was made on **09/06/2017**.
☐	This study was approved on [date] for a period of twelve months. This IRB approval will expire on [date]. Please submit a continuing review application if approval is requested beyond this date.

Consent	
☒	Please use the final version of the exempt information sheet or consent form submitted to the IRB. Contact the IRB office if you have questions about which document you should be using.
☐	The IRB approved informed consent form is attached. Use the stamped copies of this form when enrolling research participants. Each research participant should receive a copy of the consent form.
☐	This study has been approved for waiver of documentation of consent under 45 CFR 46.117(c)(1) or (2). Please use the approved consent information sheet with your participants.
☐	This study has been approved for alteration or waiving of consent under 45 CFR 46.116(d).

Study specific notifications	
☐	The IRB approved recruitment materials are enclosed with this letter. Use stamped copies of these documents for recruitment purposes.
☐	This study involves students collecting data through surveys- please review the MU Questionnaire/Survey Procedures: http://www.marquette.edu/osd/policies/survey_procedure.shtml
☐	This study involves recruitment emails for online surveys to be sent to 100 or more Marquette students, faculty or staff. Please review the website of the Online Survey Review Group: http://www.marquette.edu/onlinesurveys/

MARQUETTE UNIVERSITY
Be The Difference.

Office of Research Compliance

Schroeder Complex, 102
P.O. Box 1881
Milwaukee, Wisconsin 53201-1881

P 414.288.7570
F 414.288.6281
W marquette.edu/researchcompliance

☐	This protocol involves the use of electrical or mechanical systems that require direct human contact. Electrical and mechanical safety inspections should be conducted per Marquette University Human Research Protection Equipment and Electrical Safety Testing Policy 98.106.

HIPAA		
☐	This study involves accessing PHI from a HIPAA covered entity. The IRB has granted approval to access the following protected health information for the purpose of this study: • x	
	☐	A HIPAA Authorization form has been approved and should be used to with study subjects.
	☐	A waiver of authorization has been approved for this study.

All changes to this protocol must be reviewed and approved by the IRB before being initiated, except when necessary to eliminate apparent immediate hazards to the human subjects. If the study is exempt, please email the requested changes to orc@marquette.edu. If the study is not- exempt, please submit personnel changes using the personnel amendment form or any other changes using the amendment submission form.
If there are any adverse events or deviations from the approved protocol, please notify the Marquette University IRB immediately.
An IRB Final Report Form must be submitted once this research project is complete. The form should be submitted in a timely fashion, and must be received no later than the protocol expiration date.
The principal investigator is also responsible for ensuring that all non-Marquette study staff receive appropriate training in the ethical guidelines of conducting human subjects research. Unless a separate reliance agreement is in place, please note that approval of a study with non-Marquette investigators does not indicate that Marquette University is assuming oversight for the research activities occurring outside of Marquette's purview.

Please contact the Office of Research Compliance with any further questions. Thank you for your cooperation and best wishes for a successful project.

Jessica Rice, MPH, CIP
IRB Manager
Office of Research Compliance

Informed Consent Screen

Thank you for agreeing to participate in this study. IRB approval for this study has been obtained through Marquette University. If you have questions, please email the lead researcher Karie Ruekert Kobiske at karie.kobiske@marquette.edu.

Title of study: Pre-death Grief, Resourcefulness, and Perceived Stress Among Caregivers of Partners with Young Onset Dementia

Purpose of this study: To determine if a relationship exists between resourcefulness, grief and caregiver's stress.

Conditions of the study:

1. Anonymity will be maintained. You are not asked to give your name or personal identifiers.
2. Your participation in the surveys is completely voluntary.
3. You have the right to withdraw from the survey at any time.
4. Results of surveys will be presented in an aggregate format so it is not possible to trace results to any individual.

Benefits to participants:

1. Indirect benefit of helping health care professionals identify services, resources, and interventions that may assist caregivers of partners with young onset dementia.
2. $20.00 gift card

Risks to participants:

1. No known physical risks to participants.
2. Surveys have been used in previous studies without psychological stress to participants. However, if you become uncomfortable or psychologically distressed during responding to questionnaire items, some resources are:
    - Wisconsin's Family Caregiver Support Program and their website is: http://www.wisconsincaregiver.org.
    - Also, the State of Wisconsin maintains a general list of resources on their website: https://www.dhs.wisconsin.gov/dementia/dementiaresources.htm.
    - Alzheimer's Association. They have a 24/7 helpline (1.800.272.3900).
3. Standard risks with everyday use of computers.

By starting the survey, the participant agrees that they have read and understand the above information, have no questions, and are agreeing that they are voluntarily starting the survey and implying informed consent. Survey Completion time is estimated to be less than 30 minutes.

Demographics Screen

Demographics	Response Options
Gender	□ Male □ Female
Age	Please entre your current age _____
Race/Ethnicity	□ Caucasian □ African American □ American Indian □ Asian □ Hispanic □ Other
Educational Level	□ Less than High School (<12) □ High School (12) □ College (16) □ Graduate School (>16)
Socioeconomic Status	□ Less than $50,000. / a year □ $50,000. to $100,000. / a year □ $100,000. to $200,000. / a year □ Over $200, 000.00 / a year
Time	Please enter length of time in years since partner's initial diagnosis of Young Onset Dementia _____
Have you received counseling or therapy from a professional related to the diagnosis and/or caregiving experience	□ Yes □ No

Appendix C

Appendix C is Manuscript II which is the results and interpretations of findings for this study. This article was submitted to *Western Journal of Nursing Research* June, 27 2018.

Abstract

Over 200,000 Americans are diagnosed with young onset dementia (YOD). YOD is the dementia diagnosed prior to the age of 65. Most persons of YOD are cared for by their partners. Using the theoretical framework of Resilience Theory, this cross-sectional, correlational study examined the moderating effects of personal and social resourcefulness on the relationship between predeath grief and perceived stress among 104 YOD caregiving partners using an online survey platform. Results indicated a large positive correlation between pre-death grief and caregiver perceived stress ($r = .65$; $p < .001$). Together pre-death grief, personal resourcefulness and social resourcefulness explained 51.5% of the variance in perceived stress. Personal resourcefulness did not moderate the relationship. Social resourcefulness did positively moderate this relationship between pre-death grief and perceived stress. These findings create opportunities to better understand the needs using methodological triangulation before appropriate interventions for caregiving partners of those with YOD can be established.

Keywords: caregiver stress, partner, pre-death grief, resourcefulness, young onset dementia

Pre-Death Grief, Resourcefulness and Perceived Stress among Partners of Young Onset Dementia

Currently, more than 200,000 Americans are diagnosed with young onset dementia (YOD). YOD is any form of dementia, including Alzheimer's disease that occurs prior to the age of 65 years (Alzheimer's Association, 2018). This number is thought to underrepresent the actual incidence of YOD due to a delay in diagnosis, which frequently results from an initial misdiagnosis by primary care health professionals (Alzheimer's Association, 2018). Also, in many circumstances, there is a delay in seeking a diagnosis due to a perceived stigma by patients and families (Alzheimer's Association, 2018). YOD has been used interchangeably with the terms "early onset dementia" and "early onset Alzheimer's disease" (Alzheimer's Association, 2006). Practitioners prefer the term YOD to avoid confusion between the staging of dementia as "early dementia" or "early Alzheimer's disease" versus diagnosis prior to the age of 65 (Alzheimer's Association, 2018). YOD has occurred as early as people in their 20's and 30's but is more commonly seen in people in their 40's and 50's (Alzheimer's Association, 2018). Caregiving for a partner with YOD creates challenges resulting from changes in relationships and household dynamics (Alzheimer's Association, 2006; Flynn & Mulcahy, 2013).

Caregiving for a partner diagnosed with YOD has unique challenges including multiple losses resulting from the functional, cognitive, and behavioral declines which can be demanding and stressful for the caregiver. (Alzheimer's Association, 2006; Flynn & Mulcahy, 2013; Romero, Ott, & Kelber, 2014; van Vliet, de Vugt, Bakker, Koopmans,

& Verhey, 2010). These losses experienced by the caregiver of a partner diagnosed with YOD have been termed pre-death grief (PDG).

Caregivers of partners with YOD often report high levels of burden and stress resulting in increased incidence of depression, anxiety, hopelessness, as well as morbidity and mortality. (Alzheimer's Association, 2006; Petriwskyj. Parker, O'Dwyer, Moyle, & Nucifora, 2016). Using the theoretical framework of Resilience Theory, this study examined the moderating effect of personal and social resourcefulness of the relationship of PDG and perceived stress (PS) of YOD caregiving partners.

Resilience Theory

Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress." (American Psychology Association, 2014, p. 4). Resilience theory proposes resilience as a dynamic process of balancing risk and protective factors in the face of adversity. Protective factors can enhance resilience by balancing out risk factors which allow for greater opportunity for positive adaptation (Rutter, 1985). Resilience in caregivers of partners diagnosed with YOD is important for enhancing overall wellbeing for both the caregiver and the partner diagnosed with YOD during this devastating illness (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013; Flynn & Mulcahy, 2013). This study examined the interaction of the risk factor of PDG and the protective factor of resourcefulness on the PS of the caregiving partner.

Risk factor: Pre-death grief. Risk factors are physical or psychosocial elements that place an individual in jeopardy of maladaptation (Rutter, 1985). PDG is considered a risk

factor because it exposes family members to the risk of maladaptation and depression as they watched the social and intellectual death of their loved one due to dementia (Marwit & Meuser, 2005). Lindauer and Harvath (2014) defined the concept of PDG in caregivers of persons diagnosed with dementia as the "emotional and physical response to the perceived loss in a valued care recipient" (p. 2203). Caregivers of partners with YOD experienced PDG in the loss of the reciprocal relationship (Lindauer & Harvath, 2014; Marwit & Meuser, 2005) which has been associated with sadness, loneliness, and frustration (Flynn & Mulcahy, 2013). This differs from anticipatory grief since with PDG, there is a disruption in the relationship and in the communication with the partner resulting in a loss of personhood (Lindauer & Harvath, 2014; Marwit & Meuser, 2005). The care partner may be experiencing a loss of the partner "who use to be" even when the partner is still present in a physical sense.

Caregiving partners of a person diagnosed with YOD also experience PDG with the losses associated with job loss, financial loss, companionship loss, social loss, and other personal loss. These other personal losses include loss of personal freedom, recreation opportunities, personal identity, and personal health (Svanberg, Spector, & Stott, 2011; Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017). Additionally, there is ambiguous loss that occurs when the life partner is physically present but not able to be part of the dynamic psychosocial relationship between the couple (Frank, 2007; Svanberg et al., 2011). The partner also faces the loss of future hopes and dreams which includes the loss of all the plans the couple may have made prior to the YOD diagnosis (Wawrziczny et al., 2017).

For caregivers of persons with YOD, PDG also results from a continual loss that occurs because of the disease trajectory with new losses occurring as the dementia progresses (Lindauer & Harvath, 2014). With the progressive deterioration in functioning experienced with a YOD diagnosis, losses continue to cascade as the care recipient moves from the inability to work outside the home to inability to help around the house to inability to care for self (Alzheimer's Association, 2006; Meuser, Marwit & Sanders; 2004). Additionally, the care recipient slowly loses the ability to actively engage in social settings and in the reciprocal relationship with the caregiving partner (Alzheimer's Association, 2006; Lindauer & Harvath, 2014; Marwit & Meuser, 2005; Millenaar et al. 2016; Warchol-Biedermann et al., 2014). This downward spiral of losses compounds PDG as the caregiving partner grieves for their previous life together (Alzheimer's Association, 2006; Meuser et al., 2004; Millenaar et al. 2016; Warchol-Biedermann et al., 2014).

Protective factor: Resourcefulness. Protective factors are elements that modify an individual's risk in an adverse situation by eliminating or reducing the effects of these risk factors (Rutter, 1985). Protective factors may not operate the same in everyone. These factors are individualized and contextual that vary in each person in each situation. Resourcefulness skills have been found to be a protective factor for traditional caregivers (Bekhet, 2013; Zauszniewski, Lau, & Tithiphontumrong, 2006). Resourcefulness was originally defined as behaviors and skills that allow for adjustment against disruption (Rosenbaum, 1990). More recent definitions of resourcefulness include two complimentary parts known as personal resourcefulness and social resourcefulness (Zauszniewski et al., 2006). Personal resourcefulness is the ability to function and

maintain daily independence often referred to as "self-help" (Bekhet, 2013; Zauszniewski et al., 2006). Whereas, social resourcefulness (help-seeking) is the ability to seek out, find, and ask for help when needed (Bekhet, 2013; Zauszniewski et al., 2006). Social resourcefulness is an external process of seeking assistance from other individuals or agencies when one is no longer able to successfully manage on one's own (Zauszniewski et al., 2006). The ability to self-help and seek-help are behaviors that are important for managing stressful situations and cope with adverse events (Zauszniewski et al., 2006). Both personal and social resourcefulness skills are important for optimizing well-being, health promotion, and health maintenance.

Outcome variable: Caregiver perceived stress. Caregiver PS is the result of how unpredictable, uncontrolled, and overloaded an individual finds life events which is a frequent experience of caregivers of partners with YOD (Cohen, Kamarck & Mermelstein, 1983). In 2004, the Alzheimer's Association along with the National Alliance on Caregiving concluded that caregivers for persons with dementia carry a uniquely heavy caregiving burden due to the physically and emotionally demanding caregiving role of persons with dementia resulting in high levels of stress and taking a heavy toll on family life (Wilks & Croom, 2008). Allen and colleagues (2017) concluded, in a systematic review examining the psychobiological burden of caregiving for persons with dementia, the chronic stress of dementia caregiving results in sustained elevated cortisol level and altered immune functioning associated with depression and the development or exacerbation of chronic illness. This physical stress of YOD caregiving can exacerbate existing conditions specifically high blood pressure and diabetes (Alzheimer's Association, 2018). Also, caregivers of partners diagnosed with YOD

reported the development of depression secondary to their caregiving experience (van Vliet, et al., 2010).

Purpose

The purpose of this study was to investigate the moderating effects of both personal resourcefulness and social resourcefulness on the relationship of PDG and PS of caregivers of partners diagnosed with YOD.

Hypotheses

Hypothesis 1: Caregiver pre-death grief has a positive association with caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2a: Personal resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Hypothesis 2b: Social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

Methods

Design

The study used a cross-sectional, correlational design to assess the moderating effects of personal and social resourcefulness on the relationship of PDG and PS of YOD caregiving partners through an online survey platform.

Sample

The study included a convenience sample of 104 caregivers of partners diagnosed with YOD who were able to read and understand the English language, operate

computers, navigate the internet, and be at least 18 years old. Sample size of 100 (N = 100) was determined using G*Power (Faul, Erdfelder, Lang & Buchner, 2007) with an α = .05, β = .8 and f^2 = .1 for a small to medium effect size. Participants were recruited from various chapters of the Alzheimer's Associations in the United States, clinics specializing in dementia care, departments of aging and disability, and dementia specific centers and projects including the Dominantly Inherited Alzheimer Network (DIAN) Project Expanded Registry.

Data Collection Procedure

Institutional Review Board (IRB) approval was obtained from Marquette University prior to the initiation of the study, recruitment of caregivers of YOD, or collection of data. A convenience sample was obtained by recruiting potential subjects via IRB pre-approved fliers emailed to Alzheimer's Associations throughout Wisconsin and the United States, Departments of Aging and Disability in the State of Wisconsin, University of Kansas Alzheimer's Disease Center, DIAN Project Expanded Registry and word of mouth until the desired sample size is reached. Fliers contained a link to the survey. Participants then accessed the study at their convenience. The initial screen provided participants with background information for the study, resources for participants if needed, and an agreement for their informed consent to participate or opt out of survey. Participants were informed that their participation in the study was voluntary, internet protocol (IP) addresses would not be identified, and they could withdraw at any time without penalty. Contact information for the Alzheimer's Association, Wisconsin Family Caregiver Support Program, and State of Wisconsin resources was provided prior to participate in the study. Participants who declined the

study were not identified and the data were not collected. If participants clicked yes on the informed consent screen, the survey began with the Marwit Meuser Caregiver Grief Inventory Short Form (Marwit & Meuser, 2005), followed by the Perceived Stress Scale 14 (Cohen et al., 1983), and then the Resourcefulness Scale (Zauszniewski et al., 2006). The final screen of the survey included demographic information asking participants gender, age, education, income, and health questions. Participants were able to opt out of the survey at any time. At the completion of the surveys, participants were thanked for their participation and linked to a $20.00 gift card. Data were collected for 104 surveys via the online survey platform of Qualtrics from fall 2017 through spring 2018.

Instruments

The independent variable: Pre-death Grief. PDG was measured using the Marwit Meuser Caregiver Grief Inventory Short Form, which has acceptable inter-item correlation as demonstrated by a Cronbach's α of .96 (Marwit & Meuser, 2005). This 18-item instrument uses 5-point Likert scale ranging from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*). Scores can be determined by summing the points associated with the chosen Likert responses with total scores ranging from 18-90. Higher scores indicate greater grief (Marwit & Meuser, 2002). Examples of items include "I've had to give up a great deal to be a caregiver" (Personal Sacrifice Burden), "I have this empty, sick feeling knowing that my loved one is gone" (Heartfelt Sadness and Longing), and "The people closest to me do not understand what I'm going through" (Worry and Felt Isolation) (Marwit & Meuser, 2005, p. 199). This study used the mean score across items of the Marwit Meuser Caregiver Grief Inventory Short Form.

The moderating variable: Resourcefulness. Resourcefulness was measured using the Resourcefulness Scale (Zauszniewski et al., 2006). The 28-item Resourcefulness Scale has two different subscales; personal resourcefulness (16 items) and social resourcefulness (12 items). The Resourcefulness Scale uses 6-point Likert scale ranging from 0 (*not at all like me*), to 5 (*very much like me*). The 28 item Resourcefulness Scale scores range from 0-140 with higher scores indicating greater resourcefulness. Cronbach's α for the full scale, the Social Resourcefulness subscale, and the Personal Resourcefulness subscale were .85, .79, and .83, respectively. The personal resourcefulness subscale has 16 items with scores ranging from 0 to 80 and higher scores indicative of greater personal resourcefulness skills. An example of a personal resourcefulness item includes "When I am faced with a number of things to do, I usually plan my work" (Zauszniewski et al., 2006). The social resourcefulness subscale has 12 items with scores ranging from 0 to 60 and higher scores indicative of greater social resourcefulness skills. An example of a social resourcefulness item includes "When I am feeling sad, it helps to talk to other people" (Zauszniewski et al., 2006). For this study Personal Resourcefulness subscale scores and Social Resourcefulness subscale scores were examined independently by using the mean across items.

The dependent variable: Caregiver Stress. PS for caregivers of YOD was measured using the 14 item Perceived Stress Scale. The Cronbach's α for the Perceived Stress Scale ranged from .84 to .86 (Cohen et al, 1983). This 14-item Perceived Stress Scale uses a 5-point Likert scale ranging from 0 (*never*) *to* 4 (*very often*). Respondents are asked to respond, "fairly quickly" in a global sense about their feelings to statements such as "In the last month, how often have you been upset because of something that happened

unexpected?" (Cohen et al., 1983, p. 394). Results are obtained by using the mean across items. Seven items need to be reverse scored (Cohen et al., 1983). Higher scores indicate higher PS (Cohen et al., 1983).

Data Analysis

Data analysis was performed using R (R Core Team, 2018) with the packages lavaan (Rosseel, 2012) and semTools (SemTools Contributors, 2018). The reliability was evaluated with the maximal reliability (*MR*) coefficient. This coefficient estimates the reliability of a scale assuming items have different weights. The *MR* coefficient is the maximal possible reliability for a linear combination of the scale items. This involves the estimation of the optimal linear combination. *MR* coefficient measures reliability of a scale, unlike Cronbach alpha which estimate inter item correlation (Raykov, 2012). *MR* coefficient is estimated with the R package semTools.

Descriptive statistics were used to describe the sample. Data analysis occurred using R to evaluate bivariate correlations using Pearson's correlation coefficient (*r)* and the coefficient of determination (R^2).

The association between PDG and PS was evaluated with linear models, establishing the relation as correlation and regression. The initial relation between PDG and PS was set as a linear correlation to answer hypothesis 1. To answer hypotheses 2a and 2b, regression models were used to evaluate PDG, including personal resourcefulness, and social resourcefulness as predictors of PS. To evaluate the moderating effect of personal resourcefulness and social resourcefulness on the regression of PDG on PS, interactions between PDG and the resourcefulness scores were calculated (PDG*Personal Resourcefulness, and PDG*Social Resourcefulness) are added

as predictors of PS. The relevance of the interactions was tested by the *p*-value of the interaction regressions and the change in R^2 when the interactions are included, and finally by plotting and probing the interaction effects (Darlington, & Hayes, 2017).

Plotting and probing the interaction estimates the intercept and slope for the regression of interest (PDG → PS) conditional on the moderating variables, in this case personal resourcefulness, and social resourcefulness. This means that the intercept and slope were estimated at different values of personal resourcefulness and/or social resourcefulness, allowing for the evaluation of how personal resourcefulness and/or social resourcefulness change the regression. With probing, the null hypothesis was tested for the regression at each conditional value, while plots of these regressions were visualized (Darlington, & Hayes, 2017).

These regressions were evaluated in the framework of Structural Equation Modeling with path analysis (Kline, 2016). Missing data were handled with Full Information Maximum Likelihood, which is a proper method to handle missing data while reducing bias and increasing power since subjects are not excluded from the analysis (Enders, 2010).

Results

Descriptive Statistics

The sample consisted of 104 caregivers of partners diagnosed with YOD. The participants age ranged from 27 years old to 80 years old with a mean age of 58.27 (*SD* = 11.21). The participants had been caregiving for their partner in a range from 1 to 20 years with a mean of 5.93 (*SD* = 3.36). The majority of participants indicated that they

were white (94.74%), female (65.26%), with a college or higher education (82.11%), and an annual household income between $50,000. and $100,000 (50.53%). The remaining participants indicated that they were Asian (2.11%), Hispanic (2.11%) or African American (1.05%). The majority of participants indicated that they had not received professional counseling related to their caregiving experience (58.95%) with most rating their health in the previous month as fair or better (92.63%). The remaining participants rated their health in the past month as poor (6.32%) or terrible (1.05%).

Data Analysis Results

The total score for scales of interest were created by averaging the item scores, leading to a total score that was in the same metric as the items. The mean and standard deviations for the total scale scores are presented in Table 1 along with the *MR* coefficient (Raykov, 2012). The *MR* coefficient showed that the scales have high reliability, which indicates proper precision of measurement.

H1: Caregiver pre-death grief has a positive association with caregiver perceived stress in caregivers of a partner with YOD.

Table 2 demonstrates the correlation between scales. The relationship between PDG and PS (hypothesis 1), demonstrated a large positive correlation ($r = 0.649$, $p < .001$) showing that as PDG increases by one point the PS increases by 0.649 points. This lead to an $R^2 = 0.42$, meaning that there was 42% of shared variance between these scales.

H2a: Personal resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

H2b: Social resourcefulness moderates the relationship between pre-death grief and caregiver perceived stress in caregivers of a partner with YOD.

To answer hypotheses 2a, and 2b, two regression models were estimated. The main effects model where PS is predicted by PDG, social resourcefulness, and personal resourcefulness, which shows the effect of each predictor on PS conditional on the other predictors. The second model included the same predictors and added the interactions PDG*social resourcefulness and PDG*personal resourcefulness. This second model tested whether either personal resourcefulness or social resourcefulness moderate the relation between PDG and PS (Figure 1).

In the main effects model, PDG, personal resourcefulness, and social resourcefulness explained 51.5% of the variance in PS. When PDG, social resourcefulness, and personal resourcefulness are set to 0, the expected PS scores is 1.097 (*SE* = 0.362, *p* = .002). For the slopes, when PDG increases by 1 unit PS increases by 0.596 units (*SE* = 0.596. *p* < .001) when holding personal resourcefulness and social resourcefulness constant. As social resourcefulness increases by 1 unit PS decreases by 0.177 units (*SE* = 0.061, *p* = .004) when holding PDG and personal resourcefulness constant. Finally, as personal resourcefulness increases by 1 unit, PS decreases by 0.212 (*SE* = 0.067, *p* .001) units when holding PDG and social resourcefulness constant. The null hypothesis of these slopes being equal to 0 is rejected since their p-value was lower than .05.

When interactions are added to the regression, the R^2 increases by 0.04, meaning that these additions increase the explained variance of PS by 4%. Looking at the slopes for the interactions, the null hypothesis is rejected being equal to 0 only for the

interaction between PDG*social resourcefulness, indicating that the relation between PDG → PS is only moderated by social resourcefulness levels.

This shows that there was a moderation, but it does not indicate how the relation was being moderated. Moderation testing continued for social resourcefulness only since this was the only relevant interaction effect. Simple intercepts and slopes were tested to determine regression PDG → PS at different levels of social resourcefulness. Medium social resourcefulness was set as the average social resourcefulness for the sample, low was set as the mean minus one standard deviation, and high was set as the mean plus one standard deviation. At all three levels the social resourcefulness slope was different from 0 ($p < .05$). The regression slope was higher as social resourcefulness increased and the intercept was lower as social resourcefulness increased. This is depicted in figure 2, showing the regression slope at the three social resourcefulness values.

Lastly, PDG → PS was evaluated at continuous values of social resourcefulness. The intercept and slope were tested at social resourcefulness values ranging from ranging from 0 to 5 in 0.1 increments at 51 possible social resourcefulness values. For the intercept, as social resourcefulness increased the intercept decreased, ranging from 2.099 to -1.178. Only when social resourcefulness was higher than 1, the null hypothesis of being equal to 0 ($p < .05$) was rejected. As social resourcefulness increased the slope PDG → PS increased ranging from 0.503 to 1.052. The regressions, simple intercepts and slopes are depicted in Table 3.

Discussion

To date, this is the first study that investigated the possible moderating effect of personal and social resourcefulness on the relationship between pre-death grief and perceived stress among YOD caregivers. The results of the current study indicated that there was a high positive correlation between PDG and PS. In other words, as PDG increased, PS increased. This in fact is similar, in part, to the results of previous research that showed that caregiver well-being is negatively impacted by pre-death grief as the ever-increasing caregiving demands place these caregivers at risk for long term mental and physical health consequences including possible premature death (Paun et al., 2015).

In this study, pre-death grief accounted for 42% shared variance of caregiver stress. Caregivers of YOD report high levels of caregiver stress (Ducharme et al., 2013). Much of this stress can be accounted for with the multiple loses caregivers of partners diagnosed with YOD face. The multiple losses of PDG affecting finances, social and personal relationships combined with the loss of personhood of the partner diagnosed with YOD (Frank, 2007; Svanberg et al., 2011; Wawrziczny et al., 2017) contribute to the heavy burden and stress of caregiving partners of YOD (Allen et al., 2017; Alzheimer's Association, 2018). Programs, interventions and resources that address the specific losses faced by caregiver of partners with YOD may decrease part of the caregiver stress.

Personal resourcefulness was not found to moderate the relationship of pre-death grief and perceived stress in this study. The scale items indicators of personal resourcefulness include "when I have something to do that is anxiety arousing for me, I try to visualize how I will overcome my anxiety while doing it" and "when I am faced

with a number of things to do, I usually plan my work" (Zauszniewski et al., 2006). In fact, YOD consists of a series of continual, compounded losses. Similar to a tsunami, waves of loss continue to roll in never quite allowing the caregiver to completely adjust to the previous loss. This continual disease progression may not allow the caregiver to fully develop necessary personal resourcefulness skills as they function from one crisis to the next. Researchers agree that the mediator variable addresses how or why events occur while the moderator variable addresses when events will hold (Bennett, 2000; Barron & Kenny, 1986). Therefore, future research might look at possible mediator effects of personal resourcefulness in relation to predeath grief and perceived stress.

This unexpected finding of positive moderation of social resourcefulness on the relationship of pre-death grief and perceived stress in caregivers of partners with YOD means that as social resourcefulness increased, the relationship between predeath grief and perceived stress increased. The scale item indicators of social resourcefulness include "when I feel sad it helps to talk to other people", "when I feel confused, I depend on other people to help me", and "when my energy is low, being with other people gives me more energy" (Zauszniewski et al., 2006). A possible explanation may be related to the age of caregivers reported in this study; with a mean age of 58 years old, the majority of caregivers in this study were of working age prior to retirement. These caregivers may have been searching for age appropriate resources and experienced increased stress as they reached out to find resources and found none. This thought is in alignment with Carter, Oyebode and Koopmans' (2018) report that resources and services for both people with and caregivers of persons with YOD are "largely lacking" (p.470). Also, Wawrziczny and colleagues (2017) found that caregivers of YOD experience frustration

in their abilities to navigate the system to locate resources and services for their partner and for themselves. In a systematic review, Millenaar and colleagues (2016) found six themes that support the difficulty of YOD caregivers in which two themes speak directly to the YOD caregiver's frustrations with accessing services and with finding appropriate services. YOD caregivers with high social resourcefulness as they search for and reach out for resources and services to meet their needs may experience high levels of frustration which add to and increase their pre-death grief and stress. More research is needed to properly identify needed resources and services for this population. Using methodological triangulation, i.e. across methods design to combine both quantitative and qualitative data would be beneficial in providing more comprehensive data that would enhance understanding of the studied phenomena (Bekhet & Zauszniewski, 2012).

Since the detrimental effects of caregiver stress has been well documented, an assessment of variables that can be protective and enhance resilience in the face of risk will lead to intervention studies that have the potential to decrease perceived stress and enhance caregiver well-being. One risk factor that may contribute to caregiver stress is pre-death grief. Developing resources and services that address YOD caregiver pre-death grief may be one path to decrease caregiver stress.

Previous research has shown positive outcomes on psychological well-being for traditional dementia caregivers who are resilient (Gibson, Anderson, & Acocks, 2014). Resourcefulness has been shown to be a protective factor thereby enhancing resilience in caregivers (Bekhet, 2013; Zauszniewski et al., 2006). In fact, the ability to self-help and seek-help are behaviors are important for managing stressful situations and cope with adverse events (Zauszniewski et al., 2006). Zauszniewski and colleagues (2015) found in

a sample size of 126 female caregivers that 75% had scores that indicated a moderate to high need for resourcefulness training. Additionally, Zauszniewski's et al. (2015) results indicated that caregivers of persons with dementia could benefit from resourcefulness skill training to decrease caregiver stress. In a descriptive, cross-sectional study with 73 dementia caregivers, Bekhet (2015) found that caregivers with greater social resourcefulness had scores indicating greater psychological well-being. Resourcefulness skill building was associated with a decrease in caregiver burden and stress in these studies. In sum, previous research with traditional dementia caregivers showed that resourcefulness skills are a protective factor and can enhance adaptation and well-being (Zauszniewski et al., 2006). Therefore, it is important to better understand the lived experience of being a caregiver of someone with YOD and the resources needed as well as quality of the social resourcefulness. For example, caregivers with high social resourcefulness might seek help from others (one of the items on the Social Resourcefulness Scale) but find that the support is not available or that others do not understand their needs as a caregiver, making their pre-death grief and stress even higher. Although caregiving for someone with dementia is a challenge at any age, rather than having help of adult children, caregivers of partners with YOD may also be parenting children still in the home. Unlike those with traditional dementia, friends and families may still expect caregivers of partners with YOD to be reciprocally providing interest and support for family and community social interactions. Therefore, replication of the study by using methodological triangulation would be recommended.

Caregivers of partners with YOD are searching for meaningful support and resources to address their needs (Ducharme et al., 2013; Flynn & Mulcahy, 2013; Gibson

et al., 2014). Development of proper programming, interventions, resources and support systems, is predicted to decrease caregiver stress along with an overall increase in caregiver wellbeing (Deist & Greeff, 2015).

Limitations to this study include the use of convenience sample that was recruited by and responded using an online platform. Participants in this study needed to have access to and working knowledge of computers and the internet. Therefore, the results of the study will be generalizable only to those who are using the internet. Additional limitation includes the cross-sectional design format as this takes into account a person's responses at one moment in time. Dementia caregiving is a lengthy experience with fluctuations expected in a person's responses which may be dependent on occurring events at the time. Future studies may include longitudinal studies that evaluate these variables and how they may change over time.

References

Allen, A.P., Curran, E.A., Duggan, A., Cryan, J.F., Chorcorain, A.N., Dinan, T.G., Molloy, D.W., Kearney, P.M. & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive biological markers of stress. *Neuroscience and Biobehavioral Reviews, 73,* 123-164. doi: 10.1016/j.neubiorev.2016.12.006.

Alzheimer's Association. (2018). *2018 Alzheimer's disease facts and figures.* www.alz.org.

Alzheimer's Association. (2006). *Early onset dementia: A national challenge; a future crisis*. www.alz.org.

Alzheimer's Association & National Alliance for Caregiving (2004). *Families care: Alzheimer's caregiving in the United States.* www.alz.org/national/documents/caregiver.pdf.

American Psychological Association. (2014). *The road to resilience.* Washington, DC: American Psychological Association. Retrieved from http://www.apa.org/helpcenter/road-resilience.aspx.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of personality and Social Psychology, 51*(6), 1173-1182.

Bekhet, A.K. (2015). Resourcefulness in African American and Caucasian American caregivers of persons with dementia: Associations with perceived burden, depression, anxiety, positive cognitions, and psychological well-being. *Perspectives in Psychiatric Care, 51,* 285-294. doi: 10.1111/ppc.12095.

Bekhet, A.K., (2013). Effects of positive cognitions and resourcefulness on caregiver burden among caregivers of persons with dementia. *International Journal of Mental Health Nursing, 2,* 340-346. doi: 10.1111/j.1447-0349.2012.00877.x.

Bekhet, A. & Zauszniewski, J. (2012). Methodological triangulation: An approach to understanding data. *Nurse researcher*, *20*(2), 40-43. doi: 10.7748/nr2012.11.20.2.40.c9442.

Bennett, J. A. (2000). Focus on research methods: Mediator and moderator variables in nursing research. *Research in Nursing & Health, 23*, 415-420.

Carter, J.E., Oyebode, J.R. & Koopmans, R.T.C.M. (2018). Young-onset dementia and the need for specialist care: A national and international perspective. *Aging and Mental Health, 22*(4), 468-473. doi: 10.1080/13607863.2016.1257563.

Cohen, S., Kamarck, T. & Mermelstein R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*(4), 385-396. url: http://www.jstor.org/stable/2136404.

Darlington, R. B., & Hayes, A. F. (2017). *Regression analysis and linear models: Concepts, applications, and implementation*. New York, NY, US: The Guilford Press.

Deist, M., & Greeff, A.P. (2015). Resilience in families caring for a family member diagnosed with dementia. *Educational Gerontology, 41*(2), 93-105. doi: 10.1080/03601277.2014.942146.

Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F. & Coulombe, R. (2013). The unique

experience of spouses in early-onset dementia. *The American Journal of Alzheimer's Disease and other Dementias, 28*(6), 634-641, doi: 10.1177/1533317513494443.

Enders, C. K. (2010). *Applied missing data analysis*. New York: Guilford Press.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39,* 175-191. doi: 10.3758/BF0319346.

Flynn, R. & Mulcahy, H. (2013). Early onset dementia: The impact on family care-givers. *British Journal of Community Nursing, 18*(12), 598-606. doi:10.1177/1471301216661427.

Frank, J.B. (2007). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias. 22*(6), 516-527. doi: 10.1177/1533317507307787.

Gibson, A.K., Andersen, K.A., & Acocks, S. (2014). Exploring the service and support needs of families with early-onset Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 29*(7), 596-600. doi: 10.1177/1533317514558160.

Kline, R. B. (2016). *Principles and practice of structural equation modeling* (Fourth Edition). New York: Guilford Press.

Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing, 70*(10), 2196-2207. doi:10.1111/jan.12411.

Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist, 42*(6), 751-765. PMID: 12451156.

Marwit, S.J. & Meuser, T.M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies, 29,* 191-205. doi: 10.1080/07481180590916335.

Meuser, T., Marwit, S. & Sanders, S. (2004). Assessing grief in family caregivers. In: Doka KJ (eds). *Living with Grief: Alzheimer's disease.* Washington DC: Hospice Foundation of America, 169-198. doi: 10.1177/533317509333902.

Millenaar, J.K., Bakker, C., Koopmans, R.T.C.M., Verhey, F.R.J., Kurz, A., & de Vugt, M.E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry, 31,* 1261-1276. doi: 10.1002/gps.4502.

Paun, O., Farran, C.J., Fogg, L., Loukissa, D., Thomas, P.E., & Hoyem, R. (2015). A chronic grief intervention for dementia family caregivers in long-term care. *Western Journal of Nursing Research, 37*(1), 6-27. doi: 10.1177/0193945914521040.

Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBI Database of Systematic Reviews and Implementation Reports* doi: 10.11124/JBISRIR-2016-002555.

R Core Team (2018). *R: A language and environment for statistical computing.* R Foundation for Statistical Computing, Vienna, Austria. URL https://www.R-project.org/.

Raykov, T. (2012). Scale construction and development using structural equation modeling. In R. H. Hoyle (Ed.), *Handbook of structural equation modeling* (pp. 472-494). New York: Guilford.

Romero, M. M., Ott, C.H., & Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. *Death Studies, 38*(6), 395-403. doi: 10.1080/07481187.2013.809031.

Rosenbaum, M. (1990). *Learned resourcefulness on coping skills, self-control, and adaptive behavior.* New York: Springer Publishing.

Rosseel, Y (2012). lavaan: An R package for structural equation modeling. *Journal of Statistical Software, 48*(2), 1-36. URL http://www.jstatsoft.org/v48/i02/.

Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry, 147*, 598-611. doi: 10.1192/bjp.147.6.598.

semTools Contributors. (2018). semTools: *Useful tools for structural equation modeling. R package version 0.4-15.918.* Retrieved from https://CRAN.R-project.org/package=semTools

Svanberg, E., Spector, A. & Stott, J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatric, 23*(3), 356-371, doi: 10.1017/S1041610210001353.

van Vliet, D., de Vugt, M., Bakker, C., Koopmans, R., & Verhey, F., (2010). Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry, 25,* 1091-1100, doi: 10.1002/gps.2439.

Wachol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., & Madeda, A. (2014). What causes grief in dementia caregivers? *Achieves of Gerontology and Geriatrics, 59,* 462-467. doi: 10.1016/j.achger.2014.05.013.

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M., & Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics.* doi: 10.1111/psyg.12234.

Wilks, S.E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging and Mental Health, 12*(3), 357-365. doi: 10.1080/13607860801933323.

Zauszniewski, J.A., Lekhak, N., Au, T.Y., Yolpant, W., & Morris, D.L., (2015). Need for resourcefulness training for women caregivers of elders with dementia. *Issues in Mental Health Nursing, 36*(12), 1007-1012. doi:10.3109/01612840.2015.1075236.

Zauszniewski, J.A., Lau, C.Y., & Tithiphontumrong, S. (2006). Development and testing of a resourcefulness scale for older adults. *Journal of Nursing Measurement, 14*(1), 57-68. PMID: 16764178.

Table 1: Summary of Instruments, Descriptive and Reliabilities; *N* =104

Variables/ Concept	Measurements	Number of items	*M* (*SD*)	Possible Scores	Actual Scores	Reliability reported in this study *MR*
Independent Pre-death Grief	Marwit Meuser Caregiver Grief Inventory Short Form*	18	3.54 (0.78)	18-90	18-90	.938
Dependent Perceived Stress	Perceived Stress Scale 14*	14	2.13 (0.75)	0-56	0-53	.939
Moderating Resourcefulness	Resourcefulness Scale*	28		0-140	38-113	
Subscale	Social Resourcefulness	12	2.24 (0.91)	0-60	2-60	.919
Subscale	Personal Resourcefulness	16	3.18 (0.82)	0-80	0-74	.885

* (Cohen et al., 1983; Meuser & Marwit, 2005; Zauszniewski et al., 2006; respectively).

Figure 1: Path Analysis; *N*=104

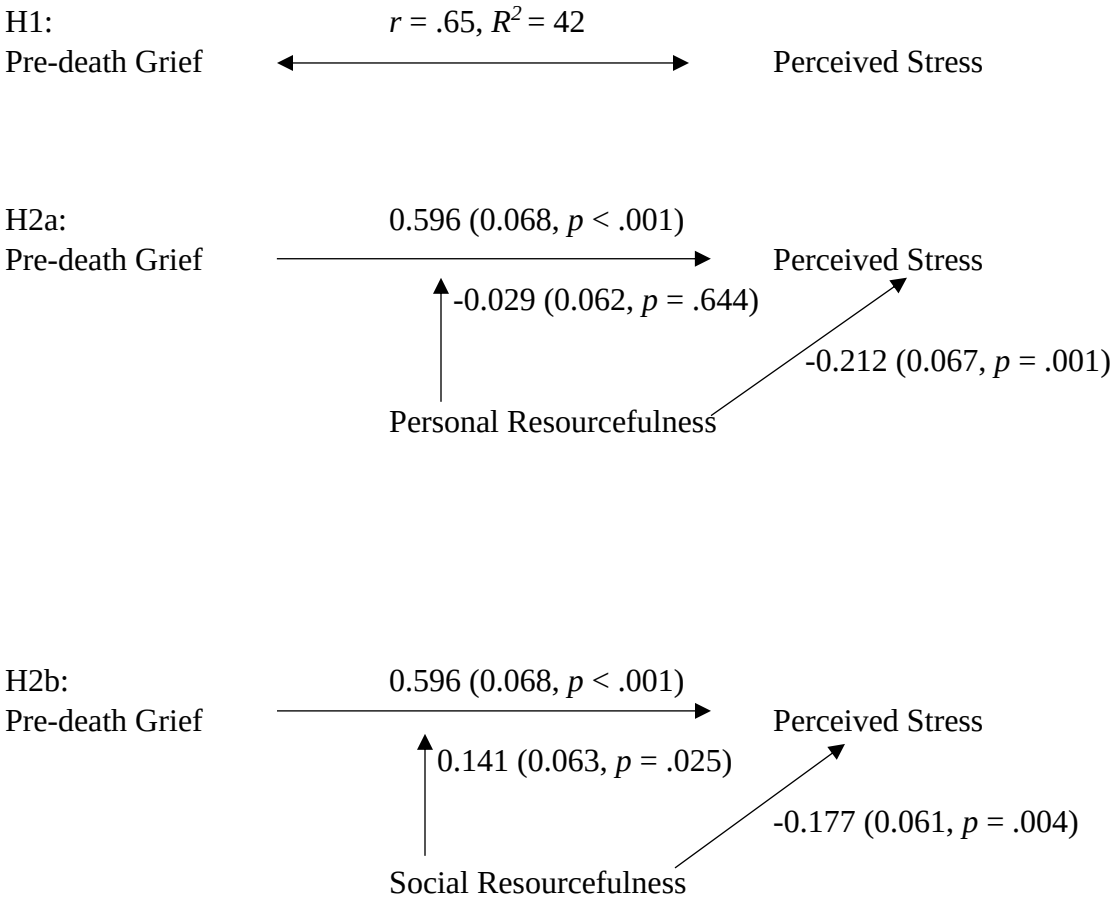


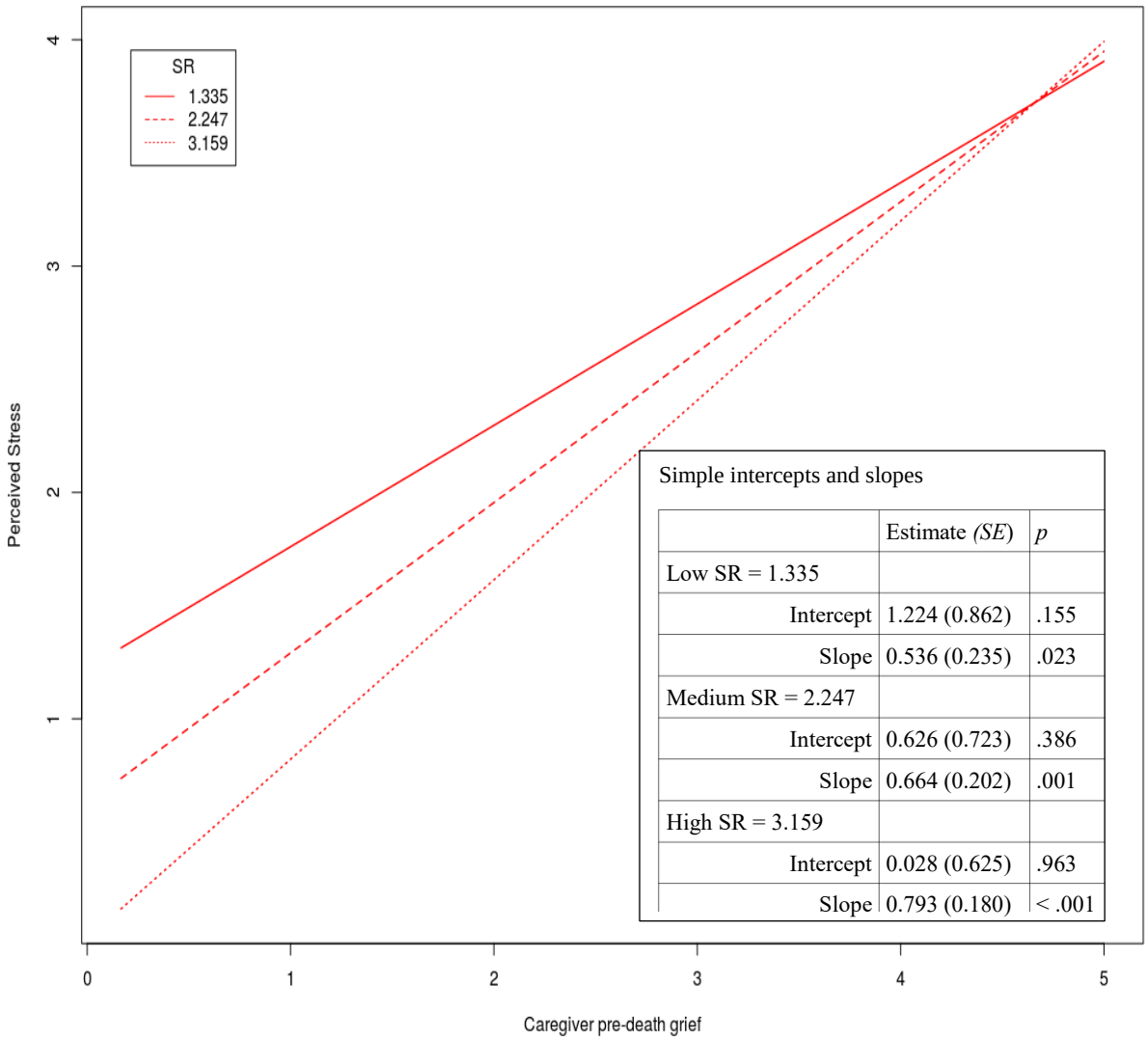
Table 2: Correlations between scales; $N = 104$

	CPDG	PSS	PR	SR
PDG	1			
PS	0.649**	1		
PR	0.070	-0.177	1	
SR	-0.198*	-0.327*	-0.041	1

*$p < .05$

**$p < .001$

Figure 2: Simple slopes 1



Simple intercepts and slopes

	Estimate *(SE)*	*p*
Low SR = 1.335		
Intercept	1.224 (0.862)	.155
Slope	0.536 (0.235)	.023
Medium SR = 2.247		
Intercept	0.626 (0.723)	.386
Slope	0.664 (0.202)	.001
High SR = 3.159		
Intercept	0.028 (0.625)	.963
Slope	0.793 (0.180)	< .001

Table 3: Simple intercepts and slopes at continuous SR

	Range of Estimate	*p*
Intercept		
SR 0 to 5	2.099 to -1.178	> .05
Slope		
SR 0 to 1	0.348 to 0.489	> .05
SR 1.1 to 5	0.503 to 1.052	< .05